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Psychosocial Influences on HIV Treatment Adherence: Utility of the Theory of Self-
Determination

by

Elena L. Ivanova

A Thesis
Submitted to the Faculty of Graduate Studies
through the Department of Psychology
in Partial Fulfillment of the Requirements for
the Degree of Master of Arts at the
University of Windsor

Windsor, Ontario, Canada

2011

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Psychosocial Influences on HIV-treatment Adherence: Utility of the Theory of Self-determination

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Declaration of Originality

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Abstract

Using the Theory of Self-Determination, the study sought to understand the factors that influence HIV treatment adherence among people living with HIV (PLWH). Fifty-seven people completed the self-report questionnaires (Phase I) and 11 took part in face-to-face interviews (Phase II). Results indicated that 42% of the sampled PLWH were not completely adherent to their HIV treatment. While the mediational hypotheses were not supported, bivariate correlations pointed to the importance of having an autonomy-supportive physician, as this variable was associated with better adherence, low depression and anxiety, higher social support, and fewer experiences of stigma. Barriers to successful adherence were experiencing side effects. Phase II findings revealed the importance of family support as a motivator for adherence. Participants also shared stories of experienced stigma in hospital settings, but these negative experiences were not related to poor adherence. Interventions should be created to guide physicians to be more supportive of patient autonomy.

Dedication

I would like to dedicate this research to all the people living with HIV and AIDS. Despite the challenges of living with HIV/AIDS and the stigma that still surrounds this health condition, everyone who I met through this research had a zest for life and ability to forgive society's ignorance. From you I learned how to see the best in people. Thank you for allowing me the opportunity to get to know you.

Acknowledgements

I am grateful for the support of my supervisor - Dr. Kathryn Lafreniere. Dr. Lafreniere's guidance, support, and commitment to community research made this project relevant and meaningful; you are a wonderful mentor and an inspiration! I also would like to thank Dr. Dennis Jackson and Dr. Eleanor Maticka-Tyndale for their expertise and thoughtful comments and suggestions. I would also like to acknowledge the Canadian Health Research Institutes (CIHR), for making this research project feasible.

Finally, I would like to express my appreciation and gratitude to my family; because of you, mom and dad, I have learned how to work hard, to dream big, and to work towards making those dreams come true - thank you Mom and Dad! My dearest brother, Roumen, you make me so proud, I wish that one day I will have as much scientific knowledge as you do. Lastly, thank you Eugene for having the patience that allowed me to chase my dreams; you are the biggest joy in my life.

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CHAPTER I

INTRODUCTION

Significance and Background

Medical advances in treatment options have significantly increased life expectancy for people living with the Human Immunodeficiency Virus (HIV; Farmer et al., 2001). As a result of these medical advances, people are living longer, healthier, and have reported an increase in their quality of life. Unfortunately, the HIV treatments known as combination Anti-Retroviral Therapy (cART), are associated with undesirable treatment-related side effects, challenging time scheduling and dietary restrictions, which contribute to patients' difficulty in adhering to this treatment (Farmer et al., 2001). In fact, the adherence rates are estimated to be as low as 27% (Kennedy, Goggin, & Nollen, 2004). Failure to comply with the HIV treatment bears many implications, such as virus mutations, higher chances of HIV viral transmission, as well as a financial burden on the health care system (Dodds, Colman, Amaratunga, & Wilson, 2000; Molassiotis et al., 2002). Research suggests that various demographic (e.g., gender), psychological, and socio-economic factors affect HIV treatment adherence (Johnson et al., 2003; Kennedy et al., 2004; Parsons, Rosof, & Mustanski, 2008; Roberts & Mann, 2000).

Few studies have investigated barriers to HIV treatment adherence from a Canadian perspective. In order to address the low adherence rates, and to improve the overall health of People Living with HIV (PLWH), further understanding of the unique psychosocial and cognitive factors that influence HIV treatment adherence needs to be gained. Using the theoretical model of Self-Determination Theory (SDT), the current study empirically examined the motivational basis of HIV treatment adherence. Of

interest, were the following general research questions: Would perception of having an autonomy-supportive physician lead to increased motivation to adhere to the HIV medications? Does social support influence a person's motivation to adhere to their HIV treatment regimen? Furthermore, does HIV-related stigma from health care providers have an influence on a person's motivation to adhere to their HIV treatment, and in turn does this predict adherence rates? Lastly, does HIV treatment-related knowledge and HIV treatment self-efficacy influence a person's motivation to adhere to their prescribed HIV treatment, and in turn does this influence HIV treatment adherence. In the present study, these research questions were examined in a sample of Ontario men and women living with HIV.

Literature Review

Prevalence of HIV in Canada. Acquired Immune Deficiency Syndrome (AIDS) is the fourth leading cause of death, globally (USAID, 2008). In Canada, in 2009, it was estimated that approximately 65,000 people were living with HIV and AIDS, a 14% increase from 2005 (57,000; Public Health Agency of Canada, 2009). Women accounted for 24% of new infections in Canada (UNAIDS/WHO, 2009). Among the Caucasian population, the most frequently reported mode of HIV transmission is homosexual contact (men who have sex with men), and secondly through intravenous drug use (38.8% and 34.7%, respectively). Among the Black population living in Canada, heterosexual contact (80.1%) is the most frequently reported mode of HIV transmission. Lastly, according to the Public Health Agency of Canada (2003), injection drug users continue to be the highest risk group among Aboriginal people, comprising 60.6% of all HIV-positive tests for this population between 1998 - 2002.

Etiology of HIV. In the beginning of the 1980s, when the first AIDS cases were recorded, HIV-specific treatments did not exist (Shilts, 1987). In fact, it took several years until scientists and clinicians were able to define and understand the cause of AIDS. The majority of the AIDS cases initially identified were young males, with illnesses such as skin cancer (Kaposi's sarcoma) or a type of lung infection (Pneumocystic pneumonia) that makes breathing difficult (Shilts, 1987). Accordingly, clinicians would prescribe the necessary treatments (i.e., antibiotics, penicillin) to manage these conditions, now known as opportunistic infections. By 1983 and 1984, the virus causing these illnesses was identified, and HIV was isolated (Durham & Lashley, 2010). Since then, scientists have proven that HIV causes AIDS. Today researchers have identified two known general strands of HIV: HIV-1 (discovered in 1984) and HIV-2 (discovered in 1986) and both strands are transmitted in the same way (Durham & Lashley, 2010). However, people infected with HIV-2 are known to be without symptoms for longer periods compared to the HIV-1 type. Although in the United States a new strain of HIV-2 has been reported, HIV-2 is generally only found in West African regions, in contrast to the HIV-1 strand, which is found worldwide (Durham & Lashley, 2010). For the remainder of the paper, the term HIV is used to denote both strands.

The process by which the HIV virus deteriorates the immune system and leads to AIDS is complex. A simplified version of this process can be described as follows: upon entering the human body, the HIV virus vastly multiplies and damages cells in the immune system associated with fighting off infections (called T-cells or killer cells), causing an infected individual to become easily sick. The process by which the HIV virus invades the human cell is a multistage one, and it begins with the HIV virus

entering the CD4 cells. The CD4 cells are white blood cells with surface receptors called CD4. These cells are important for the regulation of the immune system, as they activate killer T-cells (which fight off infections) to produce antibodies. The HIV virus targets these CD4 cells. Clinicians monitor their count because as the number of CD4 cells decrease, the HIV-infected person also declines in physical health. The CD4 cell count provides the best marker for disease progression and it is measured as the number of CD4 cells per one cubic millimeter (cells/m³). A person is said to have AIDS when the CD4 cell count is less than 200 cells/m³, compared to 600 to 1,200 cells/m³ in non-infected individuals (Durham & Lashley, 2010). The second marker of HIV progression and treatment initiation is the plasma HIV RNA (viral load). The HIV viral load is crucial in the proliferation of the HIV virus. Higher viral load units coincide with periods of higher chances of HIV transmission (Durham & Lashley, 2010). The HIV viral load is measured in units of HIV RNA copies per milliliter (cp/mL) of blood. Mellors and his colleagues (1996) established a criterion of HIV viral load and AIDS progression, showing that the higher the HIV viral load, the closer an individual is to an AIDS diagnosis (as cited in Weeks & Alcamo, 2006). For example, a viral load of 4500 cp/mL would mean that the person will likely progress to an AIDS diagnosis in approximately ten years. According to most researchers, HIV viral load of 50 cp/mL is considered an undetectable viral load stage, and thus far from progressing to an AIDS diagnosis. Prolonged suppression of the viral load, to an undetectable viral load stage, is associated with superior immune system and improved health. Clinicians also use the viral load number as an indication of the treatment being ineffective for the patient or poor treatment adherence. Clinicians suspect non-adherence (or the HIV medication not

working) when the viral load increases from less than 50 cp/mL (undetectable) to 200 or more cp/mL (Leppert & Peipert, 2004).

Medical treatment of HIV/AIDS. In treatment of HIV, neither a cure nor vaccine is available; however, there are over thirty drug treatments created for people diagnosed with HIV/AIDS to manage their health condition (Nundy, 2010).

Improvement of the physiological health for PLWH began with the introduction of Highly Active Antiretroviral Therapy (HAART). A year later, a new treatment was developed called combination Antiretroviral Therapies (cART). This treatment was more effective in treating HIV symptoms and suppressing the proliferation of the virus (Durham & Lashley, 2010). Overall, the HIV therapies suppress the HIV virus, reduce mother-to-child (vertical) transmission, and prolong survival (Durham & Lashley, 2010).

The HIV drugs are divided into classes and they are used in combination to reduce the amount of HIV in the blood (HIV viral load). Simplifying this complex process, the drugs work by blocking certain steps of the HIV proliferation (Durham & Lashley, 2010). There are six "families" of HIV medication and the classes differ at the stage of the HIV replication process that they are fighting (Durham & Lashley, 2010). For the HIV treatment to be successful, the regimen should preferably contain three different classes of medications, where patients are usually required to take multiple drugs for each class (Durham & Lashley, 2010). However, recent advances in medicine have designed some medications (e.g., Atriplia) to contain three classes of HIV medication in a single pill.

The initiation of HIV treatment is mostly based on the CD4 cell counts (Leppert & Peipert, 2004). A criterion most frequently reported is CD4 cell count below 200, or

between 200 and 350 cells/m³ (Durham & Lashley, 2010). Others report that treatment should begin at higher CD4 cell counts (i.e., > 350 cells/m³; Kitahata et al., 2009).

However, at higher CD4 counts patients may refuse treatment because they may feel healthy and starting the medication would seem unnecessary. Therefore, to achieve the best decision regarding the initiation, changing, or termination of an HIV treatment, clinicians and patients must work together to arrive at a mutual agreement (Durham & Lashley, 2010). The effectiveness of the HIV treatments is monitored by examining the viral loads and the CD4 cell counts. Although a complete viral suppression is not possible, the medications can reduce the HIV viral load to less than 50 HIV viral load cp/mL (Durham & Lashley, 2010). A viral load suppression to less than 50 HIV viral load cp/mL is an ideal cell count, referred to as HIV undetectable viral load. This can be achieved 12 to 24 weeks after treatment has begun (Durham & Lashley, 2010).

Epidemiological data on the benefits of HIV treatments show that in the USA, the number of AIDS-related deaths in 2007 was 69% lower than in 1994 (UNAIDS/WHO, 2009). In Canada, mortality rates among people living with HIV in the first five years after infection are similar to the mortality rates among the HIV-uninfected population (UNAIDS/WHO, 2009). Unfortunately, less promising data suggest that AIDS-related deaths have ceased to decline in the past few years. Failure to decrease AIDS mortality has been mainly due to the HIV treatments' inability to work for nearly 50% of patients (Halkitis, Shrem, & Zade, 2005). New drugs have been created, such as the combination antiretroviral therapies (cART), but if not taken as prescribed, these drugs will also be ineffective.

HIV treatment side effects. Several studies in the United States have suggested that concerns about side effects are the greatest barrier to successful HIV treatment adherence (Amico et al., 2007; Gao, Nau, Rosenbluth, Scott, & Woodward, 2000; Roberts & Mann, 2000). The HIV treatment side effects can be highly debilitating and lead some people to take time off their treatments (Amico et al., 2007). HIV treatments are associated with short-term and long-term physiological side effects. Some examples of short-term HIV treatment side effects are diarrhea, fatigue, and headaches (Fothergill-Bourbonnais et al., 2002; Johnson et al., 2007). The knowledge of the possible side effects (i.e., diarrhea, nausea) often leads to social isolation and in turn, diminished quality of life, making the HIV-regimens difficult to comply with (Farmer et al., 2001; Fothergill-Bourbonnais et al., 2002). Examples of long-term side effects are lipodystrophy (body weight re-distribution), high blood cholesterol, high blood sugar, neurological changes leading to delirium, and liver damage (Fothergill-Bourbonnais et al., 2002; Johnson et al., 2007). Given these side effects in combination with dietary restrictions, it is not surprising that HIV treatment adherence rates are low. In fact, 30% of HIV-positive patients reported missing at least one dose of HIV-medication in the past three days (Dunbar-Jacob, Burke, & Puczynski, 1995; as cited in Kennedy et al., 2004). Lack of HIV treatment adherence bears many consequences, such as resistance to the HIV treatment, vertical transmission (i.e., mother to child HIV transmission), and transmitting resistant strains to others (Molassiotis et al., 2002).

HIV treatment adherence. General medical adherence is defined as the extent to which patients follow the prescribed regimen corresponding with their medication, keeping up with medical appointments, obtaining inoculations, and following medical

protocols for changing behaviours, such as dieting, exercising, or cessation of cigarette smoking (Molassiotis et al., 2002; WHO, 2003). Medical non-adherence is failure to follow any of the aforementioned factors (Molassiotis et al., 2002; WHO, 2003). Across all chronic illnesses, medical adherence (treatment, diet recommendations, etc) is the most modifiable factor that can greatly increase treatment efficacy.

In research, medical adherence is operationalized in a number of ways, for example: as a percentage, a ratio (number of times missed to total doses prescribed), or categorically (i.e., good versus poor adherence; WHO, 2003). Researchers typically obtain this information either by using paper-and-pencil questionnaires, through face-to-face interviews, or electronic monitoring (i.e., pill bottle monitors). In HIV research, a commonly used questionnaire is the Adult Adherence Clinical Trial Group (AACTG), administered by an interviewer with a few self-report questions. This questionnaire defines treatment adherence as a percentage, calculated by dividing total number of doses missed by the patient, by the total number of doses prescribed, for the past three days. Researchers generally agree that a score of 95% or higher indicates successful adherence. When HIV treatment adherence falls to less than 90% it is usually associated with a significant increase in HIV viral load and is considered non-successful treatment adherence (Molassiotis et al., 2002). An alternative measure for assessing HIV treatment adherence is the Center for Adherence Support Evaluation (CASE) Adherence Index questionnaire (Mannheimer et al., 2006). This measure of HIV treatment adherence is scored out of 16, based on three Likert-type questions. A score of 10 is a marker which separates successful from poor HIV treatment adherence. This marker was obtained by comparing the CASE Adherence scores to changes in health outcomes (HIV viral loads

and CD4 cell counts), every three months for a year (Mannheimer et al., 2006). The CASE Adherence Index is a self-report measure of medication adherence and, like all self-report measures, is influenced by social desirability and recall bias, making the assessment of HIV treatment adherence complex (Chesney, Morin, & Sherr, 2000). Electronic pill bottle monitors (which count each time the pill bottle is opened), blood tests, and pharmacy prescription refill history are more reliable measures, but they are also more expensive and not easily accessible (Chesney et al., 2000). Although self-report measures have their drawbacks, most researchers rely on their use. Studies show that self-reported adherence scores can distinguish between patterns of poor and successful treatment adherence (Chesney et al., 2000; Nieuwkerk & Oort, 2005). Chesney and colleagues (2000) showed that self-report of missed medication positively correlates with HIV viral loads, which is a good physiological indicator of treatment effectiveness and disease progression (Durham & Lashley, 2010). The ubiquity of self-report measures is evident in the number of studies that have used them when evaluating HIV treatment adherence (e.g., Miguez-Burbano, Espinoza, & Lewis, 2008; Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003; Reily & Woo, 2004; Williams, Rodin, Ryan, Grolnick, & Deci, 1998). Several factors have been isolated as influencing HIV treatment adherence, and among them are personality characteristics, socioeconomic factors, and patient's mental health.

Patient Characteristics Predicting HIV Treatment Adherence

Socio-demographic factors. Past studies have suggested several psychosocial and demographic factors as influencing HIV treatment adherence. For instance, age, gender, ethnicity, and education have been reported to correlate with HIV treatment

adherence rates (Johnson et al., 2003; Ironson et al., 2005; Kennedy et al., 2004; Roberts & Mann, 2000). Mehta, Moore, and Graham (1997) reported that as age increases, HIV medical treatment compliance also increases, with the exception of the elderly (those over 75 years of age). The literature is inconsistent regarding gender differences in HIV treatment adherence. Roberts and Mann (2000) found that women who were not caring for children were more likely to adhere to their regimens as compared to men (Roberts & Mann, 2000). On the other hand, Amico and colleagues (2007) found a gender difference in HIV treatment adherence rates among their sample of PLWH. For example, more women than men endorsed the following reasons for having missed their HIV medication: 'didn't have the medication with me' (53 versus 28%), 'was feeling sick' (28 versus 10%), 'didn't want people to see me taking HIV medication' (22 versus 3%) and 'was taking a break from my HIV medications' (22 versus 0%), however, more research is needed to understand why more women felt more physically ill from the medication, which resulted in more women taking breaks from their regimen (Amico et al., 2007).

Context of location. An American research team showed that the primary predictor of HIV treatment adherence is medical insurance, a fact that is less relevant to PLWH in Canada (Mehta, Moore, & Graham, 1997). In Ontario, patients who have a valid Ontario Health Insurance (OHIP), are over the age of 65, and/or are unemployed (receiving Ontario Disability Support Program - ODSP) receive drug coverage from the Ontario Drug Benefit (ODB) plan. Typically people who are employed would have an employment health care plan and, in addition, can receive further reimbursements from the Public Service Health Care Plan (PSHCP).

Factors found to predict treatment adherence also differ for people living in rural versus urban settings. Amico et al. (2007) reported several barriers associated with living in rural areas (in the United States). Not having the medication available was found to be the most common reason for failing to take the medication on time (Amico et al., 2007). Other reasons reported were not having the medication with them or running out of the medication. In addition, Reif and colleagues (2005) reported that rural areas have significantly more barriers that prevent health care access, which in turn influences treatment adherence rates. In their study, HIV/AIDS medical managers from rural and urban areas were interviewed (Reif, Golin, & Smith, 2005). Fifty-eight percent of the rural managers identified "lack of transportation services" as the major barrier for patients to access their treatment services, while only 30% indicated this to be a "major problem" in urban areas (Reif et al., 2005). In addition, Reif and associates (2005) reported that 92% of the rural managers reported that HIV-related stigma is also a barrier for health care access, compared to 35% of the urban-based HIV/AIDS health care managers. Unfortunately, lack of access to health care services also leads to a decline in HIV treatment adherence (Reif et al., 2005).

Mental health. Being diagnosed with a chronic health condition like HIV/AIDS is a stressful event in one's life (Tucker, Brunam, Sherbourne, Kung, & Gifford, 2003). Non-clinical depression, described as daily feelings of hopelessness, denial, and avoidant coping, can have a significant negative impact on a person's health outcomes (Ironson et al., 2003). Investigators have shown that daily feelings of despair can be buffered by perceived positive social support (Simoni, Frick, & Huang, 2006). When considering clinical depression, in the years prior to an AIDS diagnosis, rates among PLWH have

been reported to be as high as 25%, and these rates increase following the development of AIDS (Lyketsos et al., 1996). Some of the negative effects associated with clinical depression, or other mental health diagnoses, are poor physical and health outcomes, and lower HIV treatment adherence rates (Cook et al., 2004; Mehta et al., 1997). A study by Cook et al. (2004) reported that HIV-positive women who were diagnosed with depression experienced faster decline in physiological health and therefore were more likely to die sooner. On the other hand, treating depression has shown to significantly increase the probability of HIV treatment adherence (Cook et al., 2006). Therefore, the role of HIV clinicians should be to also address and screen for non-physical symptoms, which would address mental health issues and in turn help HIV treatment adherence success.

Alcohol and drug dependency. Consistently, alcohol dependence has been linked with lack of HIV treatment adherence (Amico, et al., 2007; Kennedy et al., 2004; Parsons et al., 2008). In fact, a study reported that alcohol addiction decreased medical compliance by 20% (Parsons et al., 2008). However, persons regularly consuming alcohol were more likely to adhere to HIV regimens of lower complexity versus regimens of higher complexity (Parsons et al., 2008).

Despite the aforementioned psychosocial barriers to successful HIV treatment adherence, several studies show that adherence rates could be increased with proper screening and a dialogue between the HIV specialist and patient. A meta-analysis of 20 studies showed that some of the key factors influencing adherence rates are the patient's willingness to start the HIV treatment, patients' psychological distress, complexity of the HIV-regimen (dosing frequency and food instructions/timing) - factors that are amenable

to change and best understood through a clinician-patient relationship (Ammassari et al., 2002).

For patients already on HIV treatment regimens, research shows that when patients were given choice over the HIV treatments, their adherence rates were typically higher (Williams et al., 1998). Despite these positive findings, to date, an effective intervention to achieve maximum treatment adherence does not exist (Durham & Lashley, 2010; see Kalichman, Cherry, & Cain, 2005) and a better understanding of factors specific to HIV treatment adherence is needed. The overall aim of the current study was to examine HIV treatment adherence rates and the factors associated with successful treatment adherence among PLWH in southwestern and central Ontario. The theory of self-determination guided the selection of the following predictors of HIV treatment adherence: 1) the degree to which patients perceived they had autonomy over their HIV treatments (i.e., autonomy-supportive physicians); 2) patients' perceptions of HIV-related stigma from health care providers; 3) degree of HIV treatment knowledge; and lastly 4) patient-specific factors, such as perceived level of social support, HIV treatment self-efficacy, alcohol and drug use, and health locus of control. These predictors were examined in relation to HIV treatment adherence.

Theoretical Model for HIV Treatment Adherence

Self-Determination Theory

Background on self-determination theory. The theoretical model that drove the research questions in the present study was Self-Determination Theory (SDT), developed by Deci and Ryan (1985). This theory is multidimensional, consisting of cognitive and psychosocial predictors of motivation. SDT suggests that people have an innate

predisposition to be self-motivated. This innate desire can be encouraged or hindered by the social environment (Williams, Gagne, Ryan, & Deci, 2002). Self-motivation has been denoted by various names, such as intrinsic motivation, autonomous regulation, and integrated or identified motivation. For consistency in the current study, self-motivation is referred to as intrinsic motivation. In addition to intrinsic motivation, SDT distinguishes between several other types of motivations that drive people's behaviour: extrinsic motivation (also called controlled motivation), introjected intrinsic, and amotivation. Extrinsic motivation refers to behaviours done in order to attain something separate from the activity (i.e., going to the gym to get a reward). Amotivation is action without intent (going to the gym without feeling it was their choice or within their control). However, central to SDT is *intrinsic motivation*, defined as the motivation to engage in an activity because it is enjoyable, challenging or satisfying (going to the gym because exercising is pleasant). Intrinsic motivation is important because people are more likely to be persistent at a task when they are engaged because of intrinsic motivation, or out of their own volition, rather than for extrinsic reasons (i.e., someone's orders; Deci & Ryan, 2002). In addition, intrinsic motivation can also be partially intrinsic (i.e., when one is controlled by anxiety or guilt), also termed *introjected motivation*. Thus, going to the gym to avoid feeling guilty for disappointing others is an example of introjected motivation. A study by Pelletier and others (2001) highlighted the functional difference between introjected motivation and intrinsic motivation. The authors showed that introjected motivation positively predicted short-term goals, but in turn was negatively associated with long-term goals. On the other hand, intrinsic motivation was positively associated with both short-term and long-term goals (see also

Sheldon & Elliot, 1998). These results indicated the importance of intrinsic motivation, rather than only partial intrinsic motivation (or introjected motivation).

In the context of treatment adherence, intrinsic motivation is typically assessed using the Treatment Self-Regulation Questionnaire (TSRQ; Williams, McGregor, Freedman, Zeldman, & Deci, 1996). This measure has been widely used and research has found intrinsic motivation to be predictive of active participation in treatment programs, such as alcohol interventions (Ryan & O'Mally, 1995), weight loss programs (Williams et al., 1996), physical activity adherence in cancer patients (Wilson, Blanchard, Nehl, & Baker, 2005), HIV treatment adherence (Williams et al., 1998), and, in diabetes patients, high scores on intrinsic motivation were shown to correlate with better glucose level management (Williams, Freedman, & Deci, 1998).

The aim of the current study was to apply the Theory of Self-Determination to examine several psychosocial factors that could increase intrinsic motivation in PLWH and to explore whether intrinsic motivation leads to increased adherence rates to HIV treatments. Given the definition of intrinsic motivation (motivated to accomplish a task for the satisfaction of the task itself), it might be difficult to understand how patients could ever be intrinsically motivated to adhere to the taxing and arduous HIV treatment regimens. According to Self-Determination Theory, the social environment can foster intrinsic motivation, even for unpleasant tasks, when the following three psychological needs are satisfied: perceived *autonomy* (control); perceived *relatedness* (close emotional bond with others or social support); and perceived *competence* (understanding). The root notion of *autonomy* is self-rule or self-government, and in the social sciences, the term has been used to mean the capacity to govern oneself (Mele, 1995). The second

psychological factor - *relatedness* - has been defined as feeling connected to others. This need to feel connected and understood by one's social support network is not unique to this theory and social support has a vital role that influences motivation, mental health, and physical health (for review, see Reis & Patrick, 1996). Lastly, *competence* in SDT research has mainly been defined as the perceived ability to successfully complete a task. Often self-determination researchers operationalize competence as self-efficacy (defined as the expectation that a person can successfully perform a task despite the presence of adversity). SDT asserts that satisfying the three psychological needs (autonomy, relatedness, and competence) could lead to an increase in intrinsic motivation. The benefits associated with having higher intrinsic motivation are that people are more likely to engage in the behaviour if they are self-motivated. Williams, McGregor, Freedman, Zeldman, and Deci (2004) tested the SDT theory in a health care setting. The authors examined whether autonomy (allowing patients choice and control over treatments and health-related decisions) and perceived competence (the degree to which patients perceive that they can manage daily aspects of diabetes care, such as diet or exercise) among diabetes patients would be related to better management of blood sugar. This longitudinal study (baseline, six months and 12 months) tested 159 participants diagnosed with Type 2 diabetes, and asked participants to identify whether they perceived they had autonomy-supportive health care providers. The results supported the Theory of Self-Determination in that the participants who perceived themselves to have autonomy and competence were better at managing their blood sugar (glycemic) control.

Autonomy (Perceived Control)

Autonomy is characterized as *perceived control* over one's social environment. Several researchers in North America argue that most human beings actively try to shape and control their environment, as opposed to passively wait for events to occur (e.g., Deci & Ryan, 2006; Rothbaum, Weisz, & Snyder, 1982). In SDT, autonomy (along with relatedness and competence), is considered to be a basic psychological need, and failure to perceive control can lead to deleterious mental and physiological effects (e.g., Ryan & Deci, 2001). For example, Landsbergis (1988) was interested in evaluating job strain among hospital employees. A total of 289 hospital employees (61% were nurses, while the remainder were food service worker, housekeepers, social workers, etc) filled out a mail in survey. Highlighting the importance of autonomy on people's physical and mental health, the study found that job strain and burnout were significantly higher in jobs with high work demand and low decision making (low autonomy).

As previously mentioned, perceived control (autonomy) can be hindered or enhanced by the environment (Deci & Ryan, 2006). Powerful constraints on autonomy can be evaluative pressures (e.g., school grades), rewards (e.g., money), controlling behaviour (e.g., being told what to do, rather than given a choice), or punishment (Deci & Ryan, 2006). These factors have all been found to undermine autonomy, and in turn, to decrease intrinsic motivation. On the other hand, feedback and opportunity for meaningful choice have been found to facilitate intrinsic motivation in people, which is illustrated well by Thompson and Wankel (1980). These researchers recruited 36 women recently enrolled in a private health club to investigate the effect of perceived choice on the frequency of exercise behaviour. After they filled out self-report questionnaires that assessed the women's preferences for exercise, they were randomly assigned to two

groups: a control group and a choice condition. The latter group was led to believe that their activities were selected from their exercise preferences. The control group was told that they were assigned a standardized exercise program. The results indicated that the overall attendance of the choice group was significantly better than the group that was assigned an exercise program. Across both groups, participation declined over the six-week period; however, the decline was greater for the group that did not have perceived choice in their exercise program. Lastly, upon completion of the exercise program, the choice condition group expressed greater intent to continue with the program. In this study, perceived autonomy and choice were associated with higher likelihood of committing to the exercise program.

The current study examined the importance of autonomy among a sample of PLWH from Southwestern and Central Ontario. In this study, autonomy was assessed as: 1) HIV-patients' perceived autonomy over their HIV treatments (i.e., if they had autonomy-supportive physicians); and 2) Health locus of control (HLOC).

Patients' perceived autonomy over their HIV treatment (having an autonomy-supportive physician). The relationship between clinicians and patients is one of the most complex relationships, with profound effects for the patients. It is complex because unequal power positions exist between the clinician and the patient, the nature of health visits is unpleasant, the issues discussed are extremely important (Ong, De Haes, Hoos, & Lammes, 1995). Ong and colleagues (1995) published a literature review on communication between doctors and patients and reported that traditionally the clinician-patient relationship was best described as paternalistic, where the doctor instructs the patient and makes decisions regarding their treatment. The benefits

associated with avoiding the paternalistic style of communication and encouraging clinicians to share more information with their patients has profound effects for patients' health outcomes (Miller, Benefield, & Tonigan, 1993) and treatment adherence (Williams et al., 1998). In fact, research showed that patients who are informed of their health status have better coping styles and lower anxiety (Molleman et al., 1984). Molleman surveyed 418 cancer patients and found that clinicians could influence their patients' coping styles and reduce mental distress, simply by communicating more with their patients. Patients who received more information on their health status, adequate attention and understanding had better overall mental health. According to the authors, the patients' coping strategies were likely influenced because providing health related information to patients interested in knowing reduced their level of health uncertainty, which in turn influenced their coping strategies (Molleman et al., 1984).

The advantages associated with clinicians allowing more communication are undeniable, but more recently, studies have demonstrated the importance of patients' ability to have a say in the type of treatments prescribed to them. Across treatments requiring diverse lifestyle changes, clinicians who allowed patients to have control over their prescribed treatments, reported greater treatment adherence rates, more effective and long lasting smoking cessation, greater weight loss, better glucose control (in diabetes patients), and higher commitment to exercise (see Williams, 2002). For instance, Williams et al. (2002), investigated cigarette smoking cessation rates. The investigators created two interventions, with the only difference being the level of autonomy supportiveness the physicians allowed: 1) physicians were autonomy-supportive; or 2) physicians were controlling when counseling the patients to quit smoking. The

physician's level of autonomy support was rated from audiotapes. Participants' intrinsic motivation to quit cigarette smoking, as well as their perceived competence, was assessed using self-report questionnaires. Structural equation modeling indicated that the autonomy supported intervention was rated as fostering more intrinsic motivation, and in turn, intrinsic motivation predicted higher smoking cessation rates (Thorndike, Rigotti, Stafford, & Singer, 1998).

Perceived autonomy and HIV treatment adherence. Due to the complexity of HIV treatments, adequate communications for PLWH with their clinicians is of great importance (Durham & Lashley, 2010). A common reason reported for non-adherence is the complexity of the HIV regimens (Corsonello et al., 2009). Moreover, other researchers indicate that the taxing HIV-related side effects also make the regimen difficult to adhere to (Amico et al., 2007). Health care practitioners can help patients by communicating with them and tailoring the HIV treatments according to their patients' schedule and needs, as much as possible (Durham & Lashley, 2010). Williams et al. (1998) investigated 126 adult outpatients from North Carolina, with multiple diagnoses, who were on long-term medication, and had been on a particular drug regimen for at least one month. A clinical psychologist interviewed the participants, assessing each patient's levels of intrinsic motivation, their perceptions of having an autonomy-supportive physician, and HIV treatment adherence (based on recall and a prospective pill count at 2 and 14 days). Analysis revealed that intrinsic motivation significantly accounted for 68% of the variance in treatment adherence. The results demonstrated that having an autonomy-supportive physician significantly predicted HIV treatment adherence, and the effects of autonomy were mediated through intrinsic motivation.

Findings that support patients' need for autonomy over the HIV treatments prescribed are important for the implications for interventions to improve treatment adherence (Haynes et al., 1996). However, when creating interventions, it is important to keep in mind client's individual differences. Therefore, an important additional factor in assessing need for autonomy is health locus of control.

Locus of control. Locus of Control (LOC) is a belief system that people hold regarding the type of control they perceive they have over events in their lives (Rotter, 1966). Locus of control emerged from Rotter's (1954) Social Learning Theory, which posits that people learn from reinforcements. Thus, locus of control is a construct developed from past reinforcements and is sensitive to social context and past and present experiences (Rotter, 1966). LOC varies along a single continuum ranging from *External* control (forces outside oneself control events in their life, such as luck or God) on one end, and *Internal* control (personal actions control events) on the opposite end of the continuum (Rotter, 1966). Rotter suggested that the basic principle underlying LOC is that people create general expectations regarding the extent to which they are able to influence future events. Specifically, if a person has an Internal LOC, then they are likely to believe that they can have control over future events. A person with an Internal LOC orientation believes that events in their life occur because of their own behavior. In contrast, people who score high on External LOC are more passive and they believe they have less power to cause change, as they perceive that circumstances are caused by things outside of their own control, such as luck, or powerful other people (Lynam et al., 2009). Internal and External LOC are distinct from intrinsic and extrinsic motivation. These concepts are not synonyms as they stem from different theoretical backgrounds: LOC

comes from Rotter's Social Learning Theory (1966) and intrinsic/extrinsic motivation comes from causal attribution theory developed by Fritz Heider (1958). Particularly, External LOC differs from extrinsic motivation in that the former is a belief that events are not within a person's control, whereas in extrinsic motivation a person may believe they have control of events in their life (Internal LOC) but their motivation to engage in them is for external reasons (e.g., to get paid).

LOC is typically measured using self-report questionnaires, and different scales exist, depending on the construct being measured (e.g., learning, health, sports activity, etc). Wallston, Wallston, and DeVellis (1978) extended the concept of LOC to apply it to health behaviours as Health Locus of Control (HLOC) and created the Multidimensional Health Locus of Control (MHLC), which specifically measures HLOC. The MHLC is a measure that assesses the beliefs that people hold regarding the factors that can control their health (External or Internal HLOC). For instance, the generalized expectancy that a person's health depends primarily on his/her behaviour is associated with Internal HLOC. The MHLC measure includes extended constructs such as the External HLOC, which Rotter (1966) into Powerful others HLOC (e.g., Doctors) and Chance HLOC (e.g., its fate if I get sick). Therefore, the MHLC includes subscales that measure Internal, External, Chance, and Powerful Others HLOC.

Internal locus of control and health. Generally, research on HLOC and health status shows that an Internal HLOC is associated with better health related outcomes. Thus, those who believe that they are able to exercise control over their illness also have better psychological and physical management of their health condition (Affleck, Tennen, Pfeiffer, & Fifield, 1987; Molinary & Khanna, 1981). Affleck and colleagues (1987)

interviewed and administered questionnaires to 92 patients diagnosed with arthritis to study their psychosocial adjustment, illness status, HLOC over treatment of symptoms (personal, or internal, versus health care provider), and mood. Arthritis patients live with chronic and painful inflammation of the joints and the disease is characterized by unpredictable periods of painful episodes. The investigators reported that patients who perceived greater Internal HLOC as related to management of their disease (i.e., were more willing to follow recommended treatment options, etc) expressed greater positive mood and adjustment to their illness. In general, patients exhibiting Internal HLOC have more positive health outcomes because they believe that they have an influence over their arthritis symptoms, and thus their engagement in health related behaviours is higher.

Powerful others and chance locus of control. Molinari and Khanna (1981)

undertook a study that examined the relationship between HLOC, depression, and anxiety. The authors surveyed 60 male and female university students to examine their attitudes towards their HLOC orientation, including their views on Doctors HLOC and chance HLOC. The study found that high scores on powerful others HLOC were positively related to anxiety. High scores on Chance HLOC were related to depression. In turn, both anxiety and depression were found to decrease as students reported higher Internal HLOC.

Relatedness (Social Support)

Relatedness concerns the feeling of *belonging and connectedness*, often defined as social support (Deci & Ryan, 1985). Researchers using Self-Determination Theory, suggest that intrinsic motivation would be further supported if individuals feel emotional support from others (relatedness; Charbonneau, Barling, & Kelloway, 2001; Ryan,

LaGuardia, Solky-Butzel, Chirkov, & Kim, 2005). In other words, if a person perceives that they have high social support, this would increase their intrinsic motivation, and in turn increase their commitment to sports training (Tauer & Harackiewicz, 1999) or general work productivity (Baard, Decy, & Ryan, 2004), or would ameliorate the negative effects of stress among health care providers (Gottfried, 1985; Wilson, Blanchard, Nehl, & Baker, 2005). Research evaluating the effects of relatedness consistently shows that regardless of a person's age, ethnicity, or socioeconomic status, people appear to function better and report fewer psychological difficulties when they experience support, love, and affection from others (Cohen, Sherrod, & Clark, 1986; Ryan et al., 1995; Ryan, Stiller, & Lynch, 1994). A social support network can include friends, family members, coaches, subordinates, or managers, and each type has its own unique dynamics and benefits (Ryan et al., 2005). In the current study relatedness was defined with the following two factors: 1) perceived social support (from family, friends, or intimate partners); and 2) perceived HIV-related stigma from health care providers.

Perceived social support (family, friends, or intimate partners). Socially supportive relationships are generally described as help and care that others provide that leads to an increase in an individual's level of coping, health benefits, and psychological well-being (Ryan et al., 2005). Researchers have consistently found that people who feel more satisfied with their interpersonal relationships are happier and healthier than those who feel more dissatisfied with their relationships (Myers, 1992). The buffering effects of social support on mental health have been reported since the 1970s (Zimet, Dahlem, Zimet, & Farley, 1988) and recent work continues to support these findings (Chen et al., 2008). In youth (9 to 18 years of age) with asthma, Chen et al. (2008) studied social

support at the family and peer level as well as asthma severity and symptoms. Seventy-eight participants completed self-report questionnaires, were assessed on pulmonary functioning (evaluated using an electronic monitor of functional status of the lungs), and provided blood samples for a biological evaluation of asthma inflammation and symptom severity. Chen and colleagues (2008) found that lack of perceived family social support was related to increased allergic inflammation, which was related to poorer pulmonary functioning and increased asthma symptom severity, while peer social support was unrelated to asthma outcomes. More importantly, this study provided evidence for the importance of social support for people living with chronic health conditions, and the positive effects social support has on physical health functioning.

A strong social support network has been shown to have positive effects on the mental and physical health of those diagnosed with HIV (Davison, Pennebaker, & Dickerson, 2000). Studies indicate that HIV-positive people who perceive they have higher levels of social support experience less physical symptomatology, hopelessness, and depression than those with lower levels of support (Mizuno, Purcell, Dawson-Rose, Parsons, & the Suids Team, 2003; Serovich, Kimberly, Mosack, & Lewis, 2001). For example, Leserman et al. (1999) examined the effects of stress, depressive symptoms, and social support on the progression of HIV among 82 men living in North Carolina. The men were assessed using self-report questionnaires, interviews, and blood samples to measure HIV progression (CD4 cell count and HIV viral load) at six-month intervals for five and a half years. When all three variables were entered to predict HIV progression, only social support and stress had a significant correlation with the health outcome variables. Specifically, for every severe life stressor, or two moderate stressors

(measured as 4-point increase in cumulative average stressful life events), people's risk of progressing to an AIDS diagnosis doubled. In terms of social support, for each 1-point decrease in cumulative average of social support, the risk of AIDS increased almost three-fold. This research indicated that those who had lower social support were generally three times more likely to develop AIDS than their peers with higher social support. Overall, the researchers demonstrated that stress is a predictor of HIV progression and that lack of involvement with friends and family is a significant risk factor for developing AIDS.

HIV treatment adherence and social support. Health care providers are needed to decide on HIV diagnosis and proper treatments, but when it comes to treatment adherence, social relationships may be even more important than physicians (Roberts & Mann, 2000). A qualitative study asked 20 women diagnosed with HIV to keep a personal journal for one month. In the journal, the women were asked to record what their lives were like while taking the HIV treatments. The purpose of the study was to identify barriers that women faced in adhering to their HIV treatments. One of the findings that the investigators reported was that if an HIV-positive person has not informed family and friends of their HIV status, then their HIV medical adherence significantly decreased. This was true because of the difficulties associated with hiding the use of the HIV treatment from people unaware of the person's HIV status.

The chronic nature of the HIV/AIDS condition requires continuous social support (Reilly & Woo, 2004); individuals who report having a large social support network were more likely to disclose their HIV status, engage in more active coping, greater problem solving, and less avoidance (Kalichman et al., 2003). Unfortunately, many individuals

living with HIV have been found to experience higher levels of loneliness than the general population (Davies, Horton, Williams, Martin, & Stewart, 2009). The stigma associated with an HIV-positive diagnosis may contribute to loneliness and avoidance of supportive interactions (Ware, Wyatt, & Tugenberg, 2006). Davey, Foster, Milton and Duncan (2009) researched family support network and its impact on HIV progression. In this study, HIV progression was measured as HIV treatment adherence, with lower HIV treatment adherence associated with high HIV-progression among fifty youth recently diagnosed youth (ages 14 to 24 years). The study used retrospective medical review charts of participants living with HIV, and indicated that they had poor family support, both before and after HIV diagnosis. Analysis showed that for younger people living with HIV, perceived familial social support was an important predictor of acquisition of HIV and a risk for poor adherence to HIV treatment. Although treatment adherence rates decline as the AIDS-related illnesses become more severe, social support continues to be an important predictor of HIV treatment adherence, mental health, and physiological functioning (Bogart et al., 2000; Mehta et al., 1997).

Consistent with the SDT model, the proposed study investigated the role of social support (with family, friends, and intimate partners) on HIV treatment adherence. In addition, relatedness was also assessed as perceived HIV-related stigma from health care providers.

Perceived HIV-related stigma in health care settings. Since the beginning of the HIV/AIDS epidemic, some social groups have been stigmatized by the general population and even by health care professionals (see Shilts, 1987). In the first half of the 1980s, the HIV/AIDS outbreak was associated with public hysteria around the etiology of

AIDS and HIV transmission. Certain groups, such as gay males and intravenous drug users, were most associated with the illness (Herek & Glunt, 1988; Shilts, 1987). The lack of knowledge about the etiology of HIV transmission led most people to fear the members of these groups and, as a result, to stigmatize and blame them for the epidemic (Rintamaki et al., 2006). Ware and colleagues (2006) illustrated that perceived stigma contributes to marginalization and exclusion, driving people into loneliness and isolation. Approximately 30 years have passed since the first recorded cases of AIDS in North America and researchers continue to identify stigma as one of the most important social and psychological issues for people affected by HIV/AIDS (Rintakami, Davis, Skripkauskas, Bennett, & Wolf, 2006). Despite the growing number of media and educational campaigns information on HIV transmission, people continue to stigmatize PLWH (Cobb & Chabert, 2002). An extremely disappointing and discouraging fact is that similar negative attitudes are found among HIV health care providers as are seen in the general population (Cobb & Chabert, 2002). Canadian researchers, Wagner and colleagues (2010) found perceived HIV-stigma to be a barrier for immigrant women living with HIV to access fertility care. They recruited 525 HIV-positive women of reproductive age to participate in a paper-and-pencil type survey assessing women's desires and intentions to give birth in the future. HIV-related stigma, anxiety, depression, and demographic variables were assessed. Women born outside of Canada (mainly of African descent) reported experiencing judgment and HIV-related stigma by health care providers for their intentions to become pregnant.

HIV treatment adherence and perceived HIV-related stigma. Rintamaki and colleagues (2006) reported that concern over revealing HIV-status as the most significant

predictor of medical compliance. The study was based in Chicago (and nearby suburbs). The authors recruited 204 adults (mean age of 40.1 years) living with HIV to self-report their treatment adherence rates and HIV-related stigma concerns (e.g., "I am embarrassed to get my medicines from a drug store"). Approximately 20% of patients reported a high degree of concern over HIV-related stigma. Participants who experienced perceived HIV-related stigma concerns had higher non-adherence rates, as compared to participants with lower perception of stigma. This study demonstrated the important influence HIV-related stigma has on treatment adherence among PLWH. Better efforts to inform clinicians of this important barrier may improve patients' quality of life, through minimizing non-adherence rates.

Other researchers report that perceived stigma has an indirect effect on HIV treatment adherence through depression (DiIorio et al., 2007). DiIorio et al. (2007) applied a social cognitive theoretical model in predicting HIV treatment adherence. In their study, some of the social and psychological predictors were self-efficacy (confidence in taking the HIV treatment), stigma, depression, social support, and patients' satisfaction with health care providers. Structural equation modeling revealed that the best model predicting HIV treatment adherence identified self-efficacy and depression as mediators between the predictors (stigma, patients' satisfaction with health care providers, and social support) and HIV treatment adherence. Self-efficacy and depression also showed a direct and significant association with treatment adherence. Although in this study perceived HIV-related stigma was not found to be a direct predictor of HIV treatment adherence, the effect of perceived stigma was mediated through self-efficacy. Specifically, high levels of perceived stigma were associated with lower self-efficacy,

which in turn negatively affected HIV treatment adherence rates. Therefore, despite the uncertainty as to whether social stigma has a direct or indirect effect on medical adherence, stigma remains an important variable when studying HIV treatment adherence.

HIV/AIDS health care providers have a key role in the psychological and physical well being of their patients (Cobb & Chabert, 2002). One of the purposes of the current study was to examine if PLWH living in Southwestern and Central Ontario perceived HIV-stigma from their health care providers, and the possible effects that this had on HIV treatment adherence.

Competence

Most researchers using Self-Determination Theory define competence as *perceived ability to make change*. Self-determination theory suggests that when individuals perceive themselves to be competent, their intrinsic motivation increases. Numerous studies have supported this relationship (Williams, McGregor, King, Nelson, & Glasgow, 2005). For example, Bogoiien and Halvari (2005) investigated the role of competence in physical activity involvement among high school students. The students filled out questionnaires on their involvement in physical activity, their perceived competence in sports, and their level of intrinsic motivation. Statistical analysis showed positive relationships among involvement in physical activity, intrinsic motivation, and perceived sports competence. Consistent with Self-Determination Theory, the results indicated that intrinsic motivation mediated the relationship between perceived sport competence and involvement in physical activity. In the current study, competence was operationalized as HIV treatment self-efficacy and HIV treatment knowledge; both

constructs were hypothesized to be important predictors of intrinsic motivation. In turn, intrinsic motivation was hypothesized to influence HIV treatment adherence.

Self-efficacy. Self-efficacy is a concept introduced by Albert Bandura in 1977 and is described as the expectation that a person can successfully perform a task despite the presence of adversity. Self-efficacy is distinct from Internal HLOC in that the former is the ability to continue with an arduous task despite perceived barriers. On the other hand, Internal HLOC is the belief that a person has control over the task, but they may have low self-efficacy and give up if an obstacle occurs. In turn, individuals with intrinsic motivation engage in activities because they are satisfying.

Applied to health-related behaviour, self-efficacy is defined as the confidence in one's ability to comply with medical treatments, despite their complexity, the side effects, lack of social support, psychological distress, or any additional stressors and barriers (Becker & Rosenstock, 1986). The importance of self-efficacy in predicting treatment adherence has been well reported (i.e., Strecher, DeVellis, Becker, & Rosenstock, 1986). For example, in diabetes patients higher in self-efficacy for oral care was significantly associated with better dental health (Syrjala, Knecht, & Knuuttila, 2003). The concept of self-efficacy is an important factor in maintaining health behaviours, which extends to other chronic illnesses, including HIV/AIDS.

HIV treatment adherence and self-efficacy for treatment adherence. The evidence that self-efficacy accounts for some of the HIV treatment adherence rates has been well established (Cha, Erlen, Kim, Sereika, & Caruthers, 2008; Johnson et al., 2007). For example, Cha et al. (2007) examined the following predictors: perceived social support, depressive symptoms, and perceived self-efficacy, in predicting HIV treatment

adherence. The researchers administered self-report questionnaires to 215 people between the ages of 19 to 61 and living with HIV. The authors found that self-efficacy mediated the relationship between the predictors (perceived social support and depressive symptoms) and HIV treatment adherence (outcome), thus providing evidence for the importance of self-efficacy when designing interventions to target HIV treatment adherence. Johnson et al. (2006), who investigated the influence of self-efficacy and positive clinician-provider relationship on HIV treatment adherence, reported similar results. The investigators hypothesized that positive clinician-provider relationship and HIV treatment adherence would be mediated by self-efficacy. They administered self-report questionnaires to 2765 adults living with HIV and residing in the United States. The hypothesized model was supported in that self-efficacy was shown to mediate the relationship between positive clinician-patient interactions and HIV treatment adherence. This relationship was maintained after controlling for age, gender, education, health variables (CD4 cell count), depression, and social support. The importance of these findings is the suggestion that improving patients' self-efficacy can lead to better HIV treatment adherence. Focusing on helping clinicians create a positive environment for their patients, such as making them feel understood, can lead to increased self-efficacy in the patient.

Although clinicians may be communicating with patients in a respectful and compassionate way, if patients are unable to understand the medical language often spoken by clinicians, the benefits of the communication may be lost. Thus, it is relevant to explore the impact of patients' HIV treatment-related knowledge on HIV treatment adherence.

HIV Treatment Knowledge and HIV Treatment adherence. Accurate HIV treatment knowledge is needed for PLWH to successfully manage their complex medical conditions, and to successfully adhere to their prescribed HIV treatment regimens (Balfour et al., 2007). Recent literature finds support for the association between HIV treatment knowledge and better HIV treatment adherence (Balfour et al., 2007; Weiss et al., 2003). Specifically, Weiss and colleagues (2003) found that PLWH who knew the importance of adhering to the HIV treatment regimen had higher adherence rates as compared to people who were not aware that nearly perfect adherence (>95%) is needed for optimal physical health. In a more recent study by Weiss et al. (2007) the researchers reported that among the PLWH in their study, higher HIV treatment-related knowledge, as assessed by five open-ended questions (e.g., to provide a definition for viral load) was associated with better HIV treatment adherence rates. However, the majority of the published research on HIV treatment knowledge and adherence has been based in the United States, and to date less is known about the extent to which HIV treatment knowledge is associated with HIV treatment adherence in a Canadian sample of PLWH. The present study included HIV treatment knowledge as a predictor of HIV treatment adherence. The measure used for assessing HIV treatment knowledge has been validated using a Canadian sample of PLWH.

Present Study

The present study consisted of two phases aimed to examine the factors that influence HIV treatment adherence among PLWH in Southwestern and Central Ontario.

Phase I used Self-Determination Theory as a framework to understand the relationship among several psychosocial factors and HIV treatment adherence.

Specifically, three main psychological factors (perceived *autonomy*, *relatedness*, and patient's *competence*) were predicted to influence intrinsic motivation, which in turn were predicted to influence HIV treatment adherence.

The primary hypotheses were that:

H1: Intrinsic motivation would mediate the relationship between *autonomy* and HIV treatment adherence. Specifically,

H1a: Internal locus of control (Internal HLOC) would be positively related to intrinsic motivation. In turn, intrinsic motivation would be positively related to HIV treatment adherence.

H1b: Chance locus of control (Chance HLOC) would be negatively related to intrinsic motivation. In turn, intrinsic motivation would be positively related to HIV treatment adherence.

H1c: Locus of Control for Doctors (Doctors HLOC) would be negatively related to intrinsic motivation. In turn, intrinsic motivation would be positively related to HIV treatment adherence.

H1d: Other locus of control (Other HLOC) would be negatively related to intrinsic motivation. In turn, intrinsic motivation would be positively related to HIV treatment adherence.

H1e: Perceived autonomy-supportive physician would be positively related to intrinsic motivation. In turn, intrinsic motivation would be positively related to HIV treatment adherence.

H2: Intrinsic motivation would mediate the relationship between *relatedness* and HIV treatment adherence. Specifically,

H2a: Social support would be positively related to intrinsic motivation. In turn, intrinsic motivation would be positively related to HIV treatment adherence.

H2b: HIV-related stigma in health care settings would be negatively related to intrinsic motivation. In turn, intrinsic motivation would be positively related to HIV treatment adherence.

H3: Intrinsic motivation would mediate the relationship between *competence* and HIV treatment adherence. Specifically,

H3a: HIV treatment knowledge would be positively related to intrinsic motivation. In turn, intrinsic motivation would be positively related to HIV treatment adherence.

H3b: HIV treatment self-efficacy would be positively related to intrinsic motivation. In turn, intrinsic motivation would be positively related to HIV treatment adherence.

Phase II of the present study included semi-structured face-to-face interviews. The purpose of the interview component was twofold: 1) to obtain additional information on the experiences and factors associated with successful HIV treatment adherence in PLWH; 2) to gain a better understanding of the health care related experiences of PLWH; and 3) to triangulate the quantitative results with qualitative findings. The semi-structured interview questions were predetermined and a protocol was created (Appendix A), but the interview protocol was also flexible and it allowed new questions to be brought up by the interviewee. Ultimately, the present study used quantitative (Phase I) and qualitative data (Phase II) to interpret the findings.

CHAPTER II

METHOD

Phase I: Self-report Questionnaires (Quantitative Data)

Participants

Fifty-seven people living with HIV (PLWH) completed the self-report questionnaire. All participants were recruited from AIDS service organizations (ASOs) in the Greater Toronto Area. ASO clients were eligible to participate if they met the following three criteria: (1) 18 years or older; (2) have been on HIV medications for more than six months¹; and (3) able to read and write in English.

Measures

Demographics. Participants completed a demographics questionnaire assessing factors such as age, gender, sexual orientation, relationship status, ethnic/racial background, religion, educational level, income, housing situation, and two open-ended questions (Appendix B).

Health variables. Participants were asked to report their most recent CD4 cell count and HIV viral load. In addition, a list of 15 HIV treatment-related side effects was provided and participants were asked to select if any of the side effects applied to them. A choice of "other" was also provided. Participants were also asked to indicate the severity of the symptoms, on a scale from 1 (*mild*) to 7 (*severe*).

Health locus of control (HLOC). HLOC was assessed using the *Multidimensional Health Locus of Control scale-form C (MHLC-C)*. The entire MHLC-C is an 18-item self-administered questionnaire. The items were rated on a 6-point Likert

¹ Fothergill-Bourbonnais et al. (2002) argue that adjustment to the HIV treatment regimens is most difficult for patients in the first 3 to 6 months

scale, ranging from *strongly disagree* (1) to *strongly agree* (6) and it assessed participant's beliefs about the general source that influenced their specific health condition. This measure was adapted specifically for HIV/AIDS related research (Wallston, Stein, & Smith, 1994). The MHLC-C contains four dimensions of health locus of control: 1) Internal (six items); 2) Chance (six items); 3) Doctors (three items); and 4) Other (three items). The *Internal* subscale measures an individual's belief that he or she is mainly in control of his/her behaviour (e.g., "I am directly responsible for my condition getting better or worse"). The *Chance* subscale measures the extent to which one believes that their illness is a matter of fate or luck, for instance "As to my condition, what will be, will be". The *Doctors* dimension assesses people's beliefs regarding the degree of control doctors have over their illness (e.g., "If I see my doctor regularly, I am less likely to have problems with my condition"). Lastly, *Other* is a dimension of HLOC that measures an individual's expectations that other relationships, such as friends, contribute to their health condition (e.g., "The type of help I receive from other people determines how soon my illness improves"). Wallston et al. (1994) reported the internal consistency, for each of the four subscales, to range from Cronbach's alpha coefficients .85 to .87 (Internal HLOC), from .79 to .82 (Chance HLOC), from .70 to .71 (Other HLOC), and .71 for Doctors HLOC, with the Internal HLOC and Doctors HLOC correlated moderately, $r(54) = .51, p < .001$, in the present study.

HIV treatment adherence. HIV treatment adherence was measured using the *Center for Adherence Support Evaluation Adherence Index* (CASE Adherence Index; Mannheimer et al., 2006). The CASE Adherence Index consists of three items, with one of them being "When was the last time you missed at least one dose of your HIV

medications?"; the measure is designed to be quick, simple and easy to administer (Mannheimer et al., 2006), and it takes approximately two minutes to complete. Most importantly, the measure has been validated longitudinally against another HIV treatment adherence measure, the AACTG three-day self-report (Chesney et al. 2000b), and two physiological markers of HIV disease progression - HIV viral load and CD4 cell count. Using a sample of 524 PLWH, Mannheimer and colleagues (2006) compared the aforementioned measures to the CASE Adherence Index, every three months, for over an entire year. The results indicated that the CASE Adherence Index correlates with the AACTG three-day self-report ($p = .001$), and even higher associations were found with the physiological markers (i.e., HIV viral load and CD4 cell count). The CASE Adherence Index is scored out of 16. Scores that are 10 or below mark poor adherence, and scores above 10 indicate good adherence. This criterion was developed when the authors compared the CASE Adherence Index scores to patients' CD4 cell counts (Mannheimer et al., 2006). The results showed that participants who score higher than 10 on the CASE Adherence Index generally achieved a mean increase of 98 CD4 cell counts over 12 months, compared to a 41-cell increase for those who score 10 or lower, and these findings were significant ($p < .001$). Reliability data for this measure is not yet available. A secondary aim of the proposed study was to establish some of the psychometric properties of this scale.

HIV Treatment Knowledge. HIV treatment knowledge about complex treatment issues such as adherence, side effects and drug resistance was assessed using the *HIV Treatment Knowledge Scale*. This is a 21-item true and false questionnaire developed by Balfour and colleagues (2007). An example item from this measure is

"When HIV medications work well, the HIV viral load increases". In previous research, this measure has demonstrated high internal consistency, with a reliability coefficient of .90 (Balfour et al., 2007).

Self-efficacy. Self-efficacy was measured using the *HIV-Adherence Self-Efficacy Scale* (HIV-ASES), which is a measure of perceived ability to adhere to the HIV treatment, despite daily obstacles or side effects from the HIV treatment (Johnson et al., 2007). This is a 12-item scale, with a Likert-type response format ranging from 1 (*cannot do it at all*) to 10 (*certain can do it*). An example item is "How confident are you that you can stick to your treatment plan when side effects interfere with daily activities?" Higher scores indicate higher adherence self-efficacy. In previous studies, the HIV-ASES has demonstrated strong internal consistency ($> .90$; Johnson et al., 2007).

Psychological distress. The *Hospital Anxiety and Depression Scale* (HADS; Zigmond & Snaith 1983) is a 14-item self-rated questionnaire, used to assess anxious (HADS-A) and depressive (HADS-D) symptoms, with seven items for each subscale. Both subscales are measured on a 4-point Likert type scale with item scores ranging from 0 (*not at all*) to 3 (*nearly all the time*). HADS-A and HADS-D scores equal to or higher than 11 are considered definite case of high symptoms of anxiety and depression, which indicates the need for further diagnostic assessment of these disorders. Data from this measure has high test-retest reliability of $r = .74$, for up to a six month period (Savard, Laberge, Gauthier, Ivers, & Bergeron 1998). Bjelland, Dahl, Haug and Neckelmann (2002) completed a meta-analysis using 15 published studies and indicated that the internal consistency for the HADS-A varied from Cronbach's alpha coefficient of .68 to .93 (mean .83), and for the HADS-D from .67 to .90 (mean .82). The HADS provides

a reliable and valid assessment of anxiety and depression for PLWH, due to the low risk of conflation with physiological symptoms of HIV disease (Savard et al., 1998).

Intrinsic motivation. Intrinsic motivation was measured using the *Treatment Self-Regulation Questionnaire* (TSRQ), developed by Williams et al. (1996). This is a 15-item Likert-type scale with responses ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). The TSRQ measures people's involvement with health-related behaviors because of their own volition, rather than doing so as a response to external pressures. High TSRQ scores represented high internal motivation. The internal consistency for this measure, as reported by Levesque et al. (2007), is an alpha of $>.78$. An example item is "I want to take responsibility for my own health".

Autonomy-supportive physicians. To assess patients' perceptions of the degree to which their HIV-specialist is autonomy supportive, the *Health Care Climate Questionnaire* (HCCQ) was used (Williams et al., 1996). Previous research demonstrated that the reliability for this scale is a Cronbach's alpha of .96 (Williams et al., 1996). This measure assesses the amount of control and choices that patients perceive to have over their treatment as 'allowed' from their physicians. A sample item is "My doctor listens to how I would like to do things."

HIV-related stigma in health care settings. Due to the dearth of research available on health care-related HIV-stigma, a scale to measure HIV-stigma specific to health care settings was created for this study. Ten questions were developed by the author, based on knowledge from the literature on health-care related stigma, to assess HIV stigma in health care settings (Appendix C). These questions were rated on a 5-

point Likert scale, ranging from *strongly disagree* (1) to *strongly agree* (5), and an example item is "I have avoided going to dental offices because of their reactions to my HIV/AIDS". For the current study the internal consistency of this scale yielded a Cronbach's alpha of 0.86.

Perceived social support (family, friends, and intimate partners). The social support scale was adapted from the Social Provisions Scale (SPS; Cutrona & Russell, 1987). The SPS scale is an extensive measure of social support assessing six dimensions of perceived social support. For this study two subscales of the SPS were chosen to be examined - Attachment and Reliable alliance. Participants rated perceived attachment and the extent to which they can rely on family, friend, or an intimate partner for support on 4-point scales using response anchors ranging from *strongly disagree* (1) to *strongly agree* (4). The total internal consistency reliability for the Social Provisions scales has been demonstrated to be excellent ($\alpha = .93$; Cutrona & Russell, 1987).

Procedure

Recruitment. Ethics approval was obtained from the University of Windsor Research Ethics Board (REB), conforming to APA, CPA and the Tri-council Policy Statement ethical guidelines. Several AIDS Service Organizations (ASOs) agreed to participate in this study by allowing the recruitment of participants from their pool of clients. Specifically, the following ASOs in the Greater Toronto Area participated in the recruitment of participants for the self-report questionnaires: AIDS Committee of Durham (Oshawa, ON); AIDS Committee of York Region (New Market, ON); LOFT Community Services/McEwan Housing & Support Services (Toronto, ON); and Asian Community AIDS Services (ACAS; Toronto, ON). Flyers advertising the study were

posted at the aforementioned participating sites. Please refer to Appendix D for the flyer that advertised Phase I of this study.

Procedures for the self-report questionnaires. Clients who noticed the advertisements of the study and were interested in participating approached the ASO onsite-representative for a questionnaire. The onsite ASO staff presented an envelope to the participant, where directly attached on the envelope was the informed consent form (Appendix E). Once consent was obtained, that is, signed by the participant and returned to the onsite staff member, the client completed the questionnaire. The questionnaire took approximately 45 to 50 minutes to be completed. Private space for filling out the questionnaire was provided at the organization, or the participant also had the choice to complete it at another location that was convenient for them. Upon completion, or termination, of the questionnaire the participant sealed their questionnaire in the provided envelope with no identifiable information and returned the envelope to the ASO onsite representatives. At this time the participants received \$20.00 in cash for their participation, and were provided with a list of community resources (Appendix F).

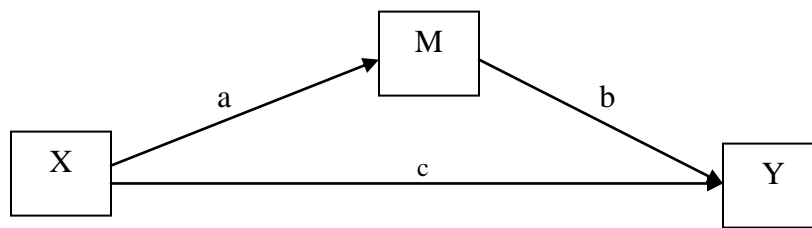
Data Analysis

Quantitative analysis. Prior to the main analysis, for descriptive purposes, frequencies of the demographic information were generated and summarized. Two-tailed Pearson product-moment correlations were used to test the influence of the predictor variables on the dependent variable (HIV treatment adherence).

Mediation analysis was used to test the main hypotheses in Phase I of the present study. Mediation is said to occur when the effect of a predictor (some variable X) on an outcome

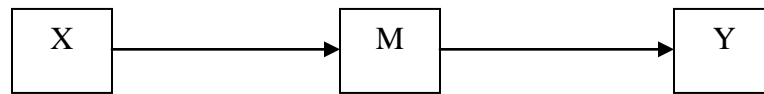
(some variable Y) is explained by a mediator variable, some variable M (see Figure 1; Shrout & Bolger, 2002). A number of techniques are available to test mediation. For example, the Baron and Kenny (1986) four-step approach has been the most influential in the past. This method, however, has received some criticisms. The main criticism of the Baron and Kenny (1986) approach is that the four steps do not test whether the indirect effect (refer to Figure 2) is significantly different from zero and whether it is in the expected direction (Preacher & Hayes, 2004).

Figure 1. Illustration for Mediation



The predictor variable is X, the mediator is M, and Y denotes the outcome variable.

Figure 2. Illustration of Indirect effect



Indirect effect does not assume the relationship between $X \rightarrow Y$ (step a, as part of the Baron and Kenny approach to testing mediation). Some authors (e.g., Shrout & Bolger, 2002) argue that $X \rightarrow Y$ is not necessary, and that the requirement of this step inflates the risk of Type II error, for the entire mediation. This is one of the criticisms for the Baron and Kenny (1986) method for mediation analysis. Shrout and Bolger (2002) explain that the $X \rightarrow Y$ relationship may not be significant because the effect may be affected by another variable (m), or other competing causes (e.g., random uncontrolled factors). Shrout and Bolger (2002), therefore, suggest that the association between $X \rightarrow Y$ may be more powerful when mediation is taken into account. The present study examines both, mediation and indirect effect.

The Sobel test has been considered more accurate; however, the assumption of normality cannot be violated (Preacher & Hayes, 2004). Especially in small sample sizes this assumption is frequently violated. Bootstrapping has been the preferred method because it does not require the assumption of normality (Preacher & Hayes, 2004). In addition, the Bootstrapping method can be used with small to moderately small sample size; that is 20 to 80 cases (Efron & Tibshirani, 1993).

The present study, therefore, used the Bootstrapping method to evaluate the mediation hypotheses, outlined on pages 36 to 37 (Preacher & Hayes, 2004). Bootstrapping is accomplished by repeatedly re-analyzing a large number of samples from the data, sampling with replacement, and computing the indirect effect, in each sample; it is recommended that the sampling with replacement is performed 5000 times (i.e., bootstrap samples; Preacher & Hayes, 2004). To use the Bootstrapping test for mediation researchers require a syntax created by Preacher and Hayes (2004). The SPSS compatible syntax can be downloaded from the author's website, available at <http://www.afhayes.com/>.

The Bootstrapping output, for mediation analyses, produces the indirect effect with 95% and 99% lower and upper bound confidence intervals. A statistically significant indirect effect does not have a zero in the confidence interval estimate (95% or 99%). This study used confidence intervals of 95% to assess if an indirect effect exists. The bootstrap output also includes the relationships among the other variables (e.g., $X \rightarrow Y$; $X \rightarrow M$, etc) as part of the mediation. Therefore, in the present study, to support mediation the following two results were required: 1) a significant relationship between

the predictor (X) and the outcome variable (Y); and 2) the Bootstrapping indirect effect also needed to be significant; that is no zero within the 95% confidence interval.

Phase II: Semi-structured Interviews (Qualitative)

Face-to-face Interviews

Narrative accounts of participants' experiences with their HIV treatments and their health care-related experiences were obtained through face-to-face semi-structured interviews. The findings from the quantitative analysis were triangulated with results obtained from qualitative analysis as further supporting evidence for the predictor variables in the proposed model. There are a number of different theoretical approaches to conducting interviews. Researchers can either have predetermined research questions in mind or conduct the interviews with a more exploratory framework. In the present study, the research questions were semi-structured and they reflected the research questions assessed by the quantitative data. The interview protocol, however, also allowed new questions to be brought up by the participant.

Participants

Eleven PLWH took part in the face-to-face interviews. All participants were recruited from AIDS service organizations (ASOs) from Windsor (ON) or downtown Toronto (ON). Participants were eligible to participate if they met the following three criteria: (1) 18 years or older; (2) have been on HIV medications for more than six months; and (3) able to understand and speak English.

Recruitment. For the recruitment of participants, flyers advertising the study were posted at the AIDS Committee of Windsor (Windsor, ON) and Fife House (Toronto, ON). AIDS Committee of Windsor (ACW) is a non-for profit organization that provides

support, education and outreach services for PLWH or for people at risk for HIV. Fife House provides affordable housing to PLWH in the Greater Toronto Area. All study flyers included the eligibility criteria, the honorarium amount, and the length of the interview (Appendix G).

Procedures for the face-to-face semi-structured interviews. Upon ethics approval from the University of Windsor, participants were recruited using flyer advertisements with a local phone number for potential participants to contact the study researcher. These flyers either were posted throughout the ASOs poster boards (AIDS Committee of Windsor), or were distributed in people's mailboxes (Fife House, Toronto). Clients who were interested in taking part in the study arranged a date and time for the interview by calling the researcher. The researcher screened every caller to assure that the potential participant met the eligibility criteria. Both participating sites provided the researcher with a private interview room. The semi-structured interviews ranged from 10.24 to 51.05 minutes in length, averaging at 22.85 minutes. The session proceeded with the participants first completing the consent forms (See Appendices H and I for general and audio consent forms). The interview started with the researcher asking an open-ended question about a specific topic, followed by prompting questions when necessary to encourage discussion (see Appendix A). Upon completion, or termination of the interview, the participants were provided with \$40.00 in cash, and were provided with a list of community resources (Appendix F).

Semi-Structured Interview Protocol

In order to correspond with findings from the quantitative analysis, the semi-structured interview questions were developed based on the variables studied (i.e.,

Autonomy-supportive health care providers, Health Locus of Control, HIV-related stigma in health care settings, social support, HIV treatment self-efficacy, and HIV treatment knowledge), as part of Phase 1 of this study. The interview questions were meant to further explore each of the aforementioned constructs, and how they related to HIV treatment adherence. For example, to represent the HIV treatment self-efficacy construct, the following question was asked: "Do you feel that you can continue taking the medication even when its interfering with your daily activities?" Please refer to Appendix A for the entire interview protocol.

Qualitative Data Analyses

The following phases were followed when analyzing the interview data:

Phase 1: Transcribed the interview data. In this phase all the audio recorded interviews were transcribed verbatim.

Phase 2: Selected quotes that represent the three constructs as part of the Theory of Self-Determination (Deci & Ryan, 1985; Autonomy, Relatedness, and Competence): In this phase, quotes were extracted that represented the predictor variables examined as part of Phase I of this study. Specifically, quotes were drawn out that best captured the respondents' HIV treatment adherence experiences and one of the following constructs: Health Locus of Control, autonomy-supportive physicians, health care-related stigma, social support, HIV treatment self-efficacy, and HIV treatment knowledge. This was done manually by re-reading the transcribed interview data and highlighting quotes that represented these constructs.

Phase 3: Reviewed for other major themes. The purpose of this phase was to be aware of other issues that the interviewee found important to share, that needed to be

included to fully capture people's experiences with taking their HIV treatment medications.

CHAPTER III

RESULTS

Phase I: Self-report Questionnaires (Quantitative Data)

All statistical analyses were performed using PASW Statistics 19.0 (SPSS Inc., 2010). The results are presented in the following four subsections: 1) data preparation; 2) descriptive analyses of the participants; 3) psychometric properties of the study measures; and 4) analyses related to the main hypotheses.

Data Preparation

The data were entered once and double-checked by another person to ensure that errors were not made when entering the data. Descriptive statistics were computed to verify the ranges for each subscale.

Expectation-maximization (EM) estimation was conducted to determine if the missing variables were missing completely at random (MCAR). This analysis estimates whether the missing values are randomly distributed across all observations, using an iterative approach examining the relation between the complete and incomplete data (Jamshidian & Bentler, 1999). If the EM estimation is $p < .05$, then the missing values depend on other values in the database; that is, the missing variables are not randomly distributed across all observations. The EM test statistics indicated that the missing variables were missing completely at random, and not systematically, $\chi^2(367, N = 57) = 389.69, p = .20$, and thus the missing responses in this study did not compromise the data. Missing data accounted for less than 5% for all the variables with the exception of the followings items: "CD4 cell count and viral load have been explained to me by my doctor" (36% missing, $n = 21$); social support (10% missing, $n = 6$); "On average, how

many doctor prescribed pills do you take daily, excluding vitamins, etc" (9% missing, $n = 5$); HIV-related stigma in health care settings (7% missing, $n = 4$); and Chance HLOC (7% missing, $n = 4$).

The missing data were handled by substituting the mean score for the scale with missing data if at least 80% of the items were answered. Pair wise deletion was used when performing the simple correlation analysis (i.e., Pearson product-moment correlations), this method allowed for more data to be retained for the analyses.

Regarding sample size, according to Efron and Tibshirani (1993) the Bootstrapping method for testing simple mediation requires small to moderately small sample size, that is 20 to 80 cases. The current study had an N of 57, and thus the study met this requirement.

The presence of outliers on the dependent variable was assessed using the standardized residuals, and values greater than ± 3 were considered outliers. The analysis did not reveal any outliers. The Bootstrapping method for testing mediation does not assume normality, thus the estimates for skewness and kurtosis were not analysed. Simple correlations among all the predictor variables were examined revealing that multicollinearity assumption was not violated (Stevens, 2000). Table 1 includes the bivariate correlations between all the variables.

Descriptive Analyses of the Participants

The majority (68%, $n = 39$) of the participants were recruited from AIDS Service Organizations (ASOs), such as the AIDS Committee of York Region, organizations that offer support services and programs to their clients. The remaining 32% ($n = 18$) of the participants in Phase I, however, were recruited from McEwan Housing and Support

Services, an ASO that provides services to highly vulnerable populations, living with HIV/AIDS, who have mental health or substance abuse challenges or both, and are homeless or at risk of becoming homeless. Therefore, the subsample recruited from McEwan Housing and Support Services was a unique sample of PLWH because of the multiple challenges that they faced. To ensure that the subsample of people recruited from McEwan Housing and Support Services were not different in their level of social support, perceived stigma, and HIV treatment adherence, a series of *t*-tests were performed to compare this subsample of participants to the remaining participants recruited from ASOs not offering housing services. The *t*-test analyses did not reveal meaningful differences between the groups on social support from family and friends ($p = .17$), HIV stigma in health care settings ($p = .97$), and on HIV treatment adherence ($p = .72$).

However, as a whole the participants who took part in Phase I were a unique subsample of the population living with HIV/AIDS, because at the time of recruitment the current sample was in contact with ASOs. This suggests that the participants in this study may have been more self-motivated to obtain the services that they required, as opposed to PLWH who were not in contact with ASOs. Also, it is likely that the people in contact with ASOs had higher social support, compared to people who were not seeking these support services. Therefore, the results from the present study should be interpreted with caution as this was not a representative sample of PLWH and this has implications for limiting the generalizability of the findings.

Demographic description of the participants. As part of the self-report questionnaire, participants were asked to indicate a number of demographic

characteristics. The sample consisted of 75.4% ($n = 43$) males and 24.6% ($n = 14$) females. Twenty-four of the males identified as gay (57.1%), 11 males (26%) identified as straight, and the remaining 14% ($n = 6$) were bisexuals. Of the female sample 71.4% were of heterosexual orientation, 2 (14.3%) were bisexual, and one participant identified as a lesbian. Participants had a mean age of 43.1 years ($SD = 9.4$). In terms of ethnicity, over one-quarter of the sample (26.3%; $n = 15$) identified as British, 26.3% ($n = 15$) were of East and Southeast Asian descent, 10.5% ($n = 6$) participants identified as Canadian, and the remaining 3.5% ($n = 2$) PLWH indicated a biracial ethnic background. Annual income was less than \$20,000 for 56.1% ($n = 32$) of the PLWH in this sample, and 63.2% ($n = 36$) of the participants indicated that they were on government assistance (i.e., Ontario Disability Support Program).

The majority of the PLWH (73.7%, $n = 42$) self-reported an undetectable HIV viral load. The average CD4 cell count was 366.30 cells/ m^3 ($SD = 336.26$); thus, this sample of participants were above the CD4 200 cells/ m^3 cut off for an AIDS diagnosis. Please refer to Table 2 for additional demographic and medical characteristics of this study sample.

Table 1

Summary of Intercorrelations for all the Predictor Variables (continuous variables)

	1	2	3	4	5	6	7	8	9	10	11
1. HCCQ	1										
MHLC-C:											
2. Internal HLC	.16	1									
3. Chance HLC	.10	.46**	1								
4. Doctors HLC	.34**	.51**	.08	1							
5. Others HLC	.17	.35**	.67**	.26	1						
6. Health care-related stigma	-.57**	-.13	.09	-.13	-.09	1					
7. Social Support	.36*	-.10	-.28	.13	-.13	-.43**	1				
8. HIV Treatment Knowledge Scale	.02	-.11	-.31*	-.09	-.24	-.19	.21	1			
9. HIV-ASES	.43**	.02	-.34*	.34*	-.17	-.14	.29*	.08	1		
10. HADS-D	-.46**	-.26	.04	-.35**	.17	.36**	-.54*	-.03	-.34*	1	
11. HADS-A	-.27*	-.10	.15	-.07	.22	.39*	-.53**	-.07	-.14	.65**	1

Note. *Correlation is significant at the 0.05 level (2-tailed), $p < 0.05$; **Correlation is significant at the 0.01 level (2-tailed). $p < 0.01$; HCCQ = Health Care Climate Questionnaire (assessing autonomy-supportive physicians); MHLC-C = Multidimensional Health Locus of Control scale-form C; HLC = Health Locus of Control; HIV-ASES = HIV-Adherence Self-Efficacy Scale; HADS-D = Hospital Anxiety Depression Scale - Depression subscale; HADS-A = Hospital Anxiety Depression Scale - Anxiety subscale.

HIV treatment adherence. With regard to HIV treatment adherence, on average the participants were successful at adhering with their prescribed HIV treatment regimen. Specifically, the average score on the CASE Adherence Index was 11.98 ($SD = 2.78$); scores higher than 10 indicated good adherence. The most frequent CASE Adherence Index score was 15.0, and four participants (7.0%) indicated 100% adherence (a score of 16). Despite these promising results, however, two-fifths of the sample, 40.4% ($n = 23$), were classified as having poor HIV treatment adherence (CASE Adherence Index ≤ 10). Table 3 summarizes the demographic and medical characteristics of the sample of people considered non-adherent (CASE Adherence Index ≤ 10) and adherent to their prescribed HIV treatment regimen (CASE Adherence Index ≥ 11). Age was significantly different between the two groups, in that the less adherent group was younger, as compared to the more adherent group.

Forty-four percent of the sample was taking 1 to 5 medically prescribed pills per day, excluding vitamins and other supplements. The participants were also asked whether they were involved in the decision to begin their HIV treatment, and 32.1% ($n = 18$) of the participants indicated yes.

Table 2

Demographic and Medical Characteristics of Study Participants (N = 57)

Characteristic	frequency	(%)	<i>M (SD)</i>
Age			43.1 (9.5)
Gender:			
Females	14	24.6	
Males	43	75.4	
Sexual Orientation:			
Straight/heterosexual	21	36.8	
Gay	24	42.1	
Lesbian	1	1.8	
Bisexual	8	14.0	
City:			
Toronto	34	59.6	
Oshawa	8	14.0	
Other	15	26.3	
Ethnic Background:			
British	15	26.3	
East/Southeast Asian	11	19.3	
African/African-Caribbean	5	8.9	
Aboriginal	4	7.0	
Other	18	35.2	
Born in Canada	30	52.6	

*Table 2 continued - Demographic and Medical Characteristics of Study Participants
(N = 57)*

Has a romantic partner	27	48.2
Employment status:		
Full/Part time work	17	29.8
ODSP	36	63.2
CPP	9	15.8
Other	10	17.6
Yearly Income:		
< 20, 000	32	59.3
20, 000-40, 000	9	16.7
> 40, 000	7	13.1
Education level:		
High School or less	18	31.6
College or more	37	64.9
Medical Variables:		
HIV viral load < 50 (Undetectable)	42	82.4
CD4 count cells/m ³		366.3 (336.2)
Number of side effects		8.5 (5.1)
Number of daily intake of pills		2.9 (1.7)
Alcohol use (per day)		1.7 (1.6)
IDU (times use per month)		1.3 (1.3)
Cannabis (times use per month)		2.1 (1.9)

Note. ODSP = Ontario Disability Support Program; CPP = Canadian Pension Plan; IDU = Injection Drug Use

Table 3

Descriptive Information of Study Participants Identified as adherent and non-adherent to their prescribed HIV treatment regimens

Variables	HIV treatment adherence		<i>p-values</i>
	Yes (<i>n</i> = 32)	No (<i>n</i> = 25)	
	<i>n</i> (%)	<i>n</i> (%)	
Age, <i>M</i> (<i>SD</i>)	45.77 (7.54)	39.82 (10.54)	.02
Gender:			.47
Male	25 (78)	18 (72)	
Female	7 (22)	7 (28)	
Ethnic Background:			.35
African	2 (6)	1 (4)	
Caribbean	2 (6)	1 (4)	
French-Canadian	4 (12)	2 (8)	
Aboriginal/Other	3 (9)	1 (4)	
Birth Place:			.27
Inside Canada	15 (50)	15 (60)	
Outside Canada	15 (50)	9 (38)	
In a relationship	16 (50)	11 (46)	
Education:			.26
Less than High School	2 (6.3)	7 (28)	
High school or higher	29 (91)	18 (72)	
Income:			.44

Table 3 continued - Descriptive Information of Study Participants Identified as adherent and non-adherent to their prescribed HIV treatment regimens

<20, 000	16 (52)	16 (70)	
20, 000-40, 000	6 (19)	3 (13)	
>40, 000	4 (13)	3 (13)	
Full-time/Part-time	10 (31)	6 (24)	.67
On government assistance	20 (62)	16 (64)	.59
Medical variables:			
CD4 count cells/m ³ , <i>M (SD)</i>	352.34 (279.8)	384.16 (402.7)	.48
Undetectable viral load	25 (83)	17 (81)	.87
# of side effects, <i>M (SD)</i>	9.2 (5.3)	7.6 (4.9)	.37

Note. Significance test for frequency variables were conducted using chi-square analysis; *t*-test was conducted for continuous predictors; Yes = good HIV treatment adherence (CASE Adherence Index ≥ 11); No = poor HIV treatment adherence (CASE Adherence Index ≤ 10).

Side effects due to the HIV medications. Participants were asked to indicate if they had experienced any HIV treatment-related side effects, and if yes, they were asked to indicate the severity of those symptoms (out of 7). The most *common* side effect, as indicated by 82.5% of the participants ($n = 47$), was weakness, and the average severity of this side effect was 4.24 ($SD = 1.99$). The most *severe* side effect ($M = 4.63$, $SD = 1.73$) was trouble falling asleep, and 63.2% ($n = 36$) of the participants indicated that they had trouble falling asleep. Table 4 lists all the identified HIV treatment-related side effects, their average severity level as indicated by the participants, and the relationship between the indicated side effects and HIV treatment adherence (CASE Adherence Index). Headache severity was significantly correlated with HIV treatment adherence, in that the higher the severity of this HIV treatment-related side effect (i.e., headache) the greater the reduction in HIV-treatment adherence.

Twenty-one participants (37.5%) indicated that their HIV treatment side effects were stopping them from doing their everyday activities. Despite this high percentage according to the HIV-ASES scale, based on a measure of HIV treatment self-efficacy (i.e., perceived ability to be able to adhere to the HIV treatment despite obstacles), the participants' HIV treatment self-efficacy was very high. The average score on the HIV-ASES was 90.53 ($SD = 24.55$), and the scale ranged from 0 to 120, which indicated that the participants had high HIV treatment self-efficacy to adhere to their prescribed HIV treatments.

Table 4

Side effects due to the HIV treatment, sorted by the most common to the least commonly reported side effect, correlated with HIV treatment adherence

HIV treatment side effect	<i>n</i>	%	<i>M</i> severity	<i>SD</i>	<i>r</i>
Weakness (fatigue)	47	82.5	4.24	1.99	-.07
Body Fat Changes	41	71.9	3.85	2.22	-.03
Decreased Memory	40	70.2	3.44	2.06	-.10
Night Sweats	38	66.7	3.57	2.18	-.30
Trouble Falling Asleep	36	63.2	4.63	1.73	-.02
Headaches	35	61.4	3.34	1.88	-.37*
Bodily Pain	35	61.4	4.47	2.18	.04
Feeling Sad	33	57.9	3.37	2.11	-.21
Diarrhea	31	54.4	3.52	1.77	-.09
Dizziness	29	50.9	3.48	2.11	-.25
Weight loss	29	50.9	3.14	1.98	-.24
Sexual dysfunction	24	42.1	3.96	2.25	-.17
Rash	24	42.1	2.50	1.64	.32
Vomiting	20	35.1	3.10	2.31	-.32
Fever	17	29.8	2.29	1.57	-.25
Other:					
Wasting disease	1	0.5	7	-	-
Neuropathy	1	0.5	-	-	-

Note. *Correlation is significant at the 0.05 level (2-tailed), $p < 0.05$

Psychometric Properties of the Study Measures

Reliability Analyses. Cronbach's Alpha was calculated on the nine main variable measures: the *CASE Adherence Index* (Mannheimer et al., 2006), the *Health Care Climate Questionnaire* (HCCQ; Williams et al., 1996), *Internal Health Locus of Control (HLC)*, *Chance HLC*, *Doctors HLC*, and *Others HLC* subscales as part of the *Multidimensional Health Locus of Control Scale (MHLC)*, the *Treatment Self-Regulation Questionnaire* (TSRQ; Williams et al., 1996), the *HIV Treatment Knowledge Scale* (Balfour et al., 2007), the *HIV-Adherence Self-Efficacy Scale (HIV-ASES)* (Johnson et al., 2007); the *Hospital Anxiety and Depression Scale* (HADS; Zigmond & Snaith, 1985); social support, and health care-related HIV stigma. The results are summarized in Table 5. All self-report measures showed adequate ($\alpha > .7$) to excellent ($\alpha > .9$) internal consistency, with the exception of the CASE Adherence Index, HIV-treatment knowledge, Doctor, and Other HLOC. The latter four measures had very low internal consistency, ranging from .32 to .58; these measures consisted of only three items, which was likely to have contributed to their low internal consistency. Measures with low internal consistency can decrease the likelihood of finding a statistical difference, and thus increasing the risk of Type II error. All the scales, however, were retained for the statistical analysis.

Table 5

Reliability of the Study Measures

Measure	<i>N</i>	<i>M</i>	<i>SD</i>	Possible Range	Actual Range	# of items	α
CASE Adherence Index Questionnaire	55	11.98	2.78	3-16	6-16	3	.52
MHLC - C:							
Internal HLC	55	20.90	6.60	6-36	6-36	6	.79
Chance HLC	53	16.34	6.37	6-36	6-31	6	.75
Doctor HLC	56	14.34	3.14	3-18	8-18	3	.58
Other HLC	56	10.12	3.11	3-18	3-16	3	.32
HCCQ	57	86.06	21.76	15-105	15-105	15	.94
Social Support	51	25.04	4.71	8-32	10-32	8	.80
Health care-related stigma	53	28.52	9.80	10-50	10-50	10	.86
HIV-ASES	54	90.53	24.55	0-120	21-120	12	.91
HIV Treatment Knowledge Scale	55	18.48	2.31	0-21	8-21	21	.46
TSRQ	52	66.88	16.18	15-105	15-102	15	.83

Table 5 continued - Reliability of the Study Measures

HADS:

HADS-A	55	8.47	4.04	0-21	2-17	7	.68
HADS-D	55	6.79	5.48	0-21	0-20	7	.87

Note. α = Internal consistency, Alpha coefficient; HLC = Health Locus of Control; MHC-C = Multidimensional Health Locus of Control Scale; HCCQ = Health Care Climate Questionnaire; HIV-ASES = HIV-Adherence Self-Efficacy Scale; TSRQ = Treatment Self-Regulation Questionnaire; HADS = Hospital Anxiety and Depression Scale; HADS-A = Hospital Anxiety and Depression Scale - Anxiety subscale; HADS-D = Hospital Anxiety and Depression Scale - Depression subscale.

Correlational Analyses

Relationships between the predictor and demographic variables and HIV treatment adherence. Two-tailed Pearson product-moment correlations were used to examine the relationship among the demographic variables, medical characteristics, the predictor variables (MHLC, HCCQ, Health care-related Stigma, Social Support, HIV Treatment Knowledge Scale, and HIV-ASES), and HIV treatment adherence (CASE Adherence Index; Table 6). Age was positively correlated with HIV treatment adherence, $r(51) = .31, p = .02$; that is, the older sample of PLWH in this study had better adherence rates. Perceived autonomy-supportive health care provider (HCCQ) was marginally associated with HIV treatment adherence, $r(53) = .26, p = .05$. People who perceived that they had autonomy-supportive physicians had higher HIV treatment adherence scores. Interestingly, people who perceived that their doctor had high influence on their health (i.e., high on Doctors HLOC) also had high scores on the CASE Adherence Index (HIV treatment adherence), $r(53) = .31, p = .02$. Lastly, a medium effect was found between HIV treatment self-efficacy (HIV-ASES) and HIV treatment adherence, $r(52) = .40, p = .003$, which indicated that as a person's efficacy to adhere to the HIV-treatment increased, their adherence to the HIV treatment also increased.

Table 6

Pearson Correlations between HIV treatment Adherence and Demographics, Medical characteristics, and the Predictor Variables

Characteristics	<i>R</i>	<i>p</i> -value	<i>n</i>
Age	.31 [*]	.02	53
Gender	.16	.24	55
Education level	.18	.09	55
In a relationship	.07	.60	55
Employment status:			
Full/Part time working	.11	.43	55
On government assistance	-.07	.59	55
Alcohol and Substance Use:			
Alcohol consumption (daily)	.05	.74	54
IDU use (monthly)	.07	.59	55
Cannabis use (monthly)	-.25	.06	55
Medical Characteristics:			
Undetectable Viral load	-.10	.47	50
CD4 count cell count	-.06	.65	55
Daily medication intake	-.07	.64	51
Number of side effects	.12	.40	55
Side effects interfere with daily activities	.23	.09	55
I was involved in the decision to begin the HIV treatment	-.02	.90	57

Table 6 continued - Pearson Correlations between HIV treatment Adherence and Demographics, Medical characteristics, and the Predictor Variables

HIV medications are necessary	.12	.38	54
TSRQ (intrinsic motivation)	.12	.38	51
HCCQ (autonomy-supportive physician)	.26*	.05	55
MHLC-C:			
Internal HLC	.22	.11	54
Chance HLC	-.05	.73	52
Doctors HLC	.31*	.02	55
Others HLC	.05	.72	55
Social Support	.09	.53	50
Health care-related stigma	-.11	.42	52
HIV Treatment Knowledge Scale	-.13	.36	54
HIV-ASES (HIV treatment self-efficacy)	.40**	.003	54
HADS-A	.02	.86	54
HADS-D	-.14	.15	54

Note. *Correlation is significant at the 0.05 level (2-tailed), $p < 0.05$; **Correlation is significant at the 0.01 level (2-tailed), $p < 0.01$; TSRQ = Treatment Self-Regulation Questionnaire; HCCQ = Health Care Climate Questionnaire; MHLC-C = Multidimensional Health Locus of Control scale-form C; HLC = Health Locus of Control; HIV-ASES = HIV-Adherence Self-Efficacy Scale; HADS-A = Hospital Anxiety Depression Scale - Anxiety subscale; HADS-D = Hospital Anxiety Depression Scale - Depression subscale.

Relationships among the predictor variables only. An examination of Table 1 revealed several significant relationships amongst the predictor variables. Specifically, HCCQ (autonomy-supportive physician) was positively correlated with Doctors HLOC, $r(54) = .34, p < .01$, and HIV-ASES (HIV treatment self-efficacy), $r(52) = .43, p < .01$. That is, participants who perceived having an autonomy-supportive physician also believed that their physician had a lot of control over their health, but they also had high HIV treatment self-efficacy to take their HIV treatment despite obstacles. Furthermore, the HCCQ was negatively correlated with the following variables: health care-related stigma, $r(51) = .44, p < .01$, depression symptoms, $r(53) = -.46, p < .01$, and anxiety symptoms, $r(53) = -.27, p < .05$; indicating that people who perceived having an autonomy-supportive physician also perceived less HIV-related stigma in health care settings, had lower depressive symptoms, and lower anxiety.

Internal HLOC was positively correlated with the other MHLC-C subscales; specifically, it was significantly and positively associated with Chance HLOC, $r(51) = .46, p < .01$, Doctors HLOC, $r(53) = .51, p < .01$, and others HLOC, $r(53) = .35, p < .01$.

Chance HLOC was negatively correlated with HIV treatment knowledge, $r(49) = -.31, p < .05$ and HIV treatment self-efficacy, $r(49) = -.34, p < .05$. This indicated that people who scored high on Chance HLOC, that is, those who believed that aspects outside of their control influenced their health, had lower HIV-related treatment knowledge and lower self-efficacy to adhere to the HIV-treatment. Chance HLOC and Other HLOC were highly and positively correlated with each other, $r(51) = .67, p < .01$.

Doctors HLOC scale was positively associated with HIV-ASES (HIV treatment self-efficacy), $r(52) = .34, p < .05$, and negatively correlated with symptoms of

depression, $r(53) = -.35, p < .01$; meaning that participants who believed that their physicians had control of their health, also had higher HIV treatment self-efficacy, and lower depression scores.

HIV-related stigma in health care settings was negatively associated with perceived social support, $r(48) = -.43, p < .01$; that is, greater HIV-related stigma measure was associated with lower perceived social support. Health care-related stigma was positively associated with depression, $r(49) = .36, p < .05$, and anxiety $r(49) = .39, p < .05$.

Social support was positively correlated with HIV-ASES, $r(47) = .29, p < .05$, suggesting that perceptions of high social support were associated with high self-efficacy to adhere to the HIV treatment despite difficulties with the treatment. Low scores on social support, on the other hand, were associated with higher levels of depression, $r(48) = -.54, p < .05$, and anxiety, $r(48) = -.53, p < .01$.

Symptoms of depression negatively correlated with the HIV-ASES scale (HIV treatment self-efficacy), $r(51) = -.34, p < .05$, suggesting that people who had higher depressive symptoms were more likely to have low HIV treatment self-efficacy scores. Lastly, symptoms of anxiety (HADS-A) and depression (HADS-D) were highly and positively correlated, $r(53) = .62, p < .01$, suggesting that these conditions tended to be co-morbid in this sample of PLWH.

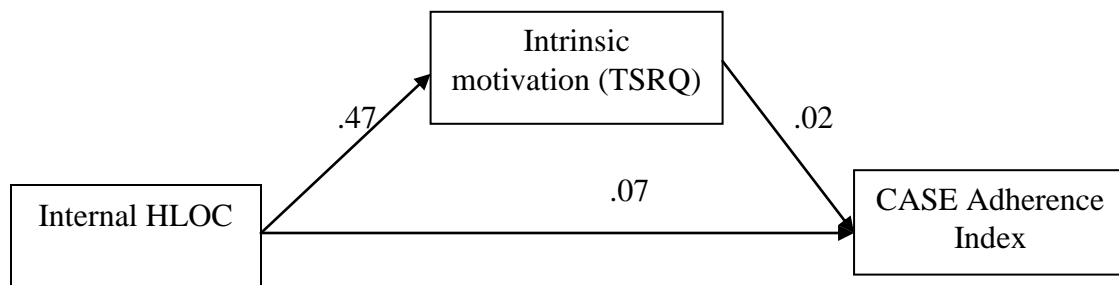
Analyses Related to the Main Hypotheses

Hypotheses 1a to 1e stated that intrinsic motivation (TSRQ) would mediate the relationship between *autonomy* (Internal, Chance, Doctors, and Others HLOC, and HCCQ) and HIV treatment adherence (CASE Adherence Index). Figures 3 to 7

illustrate these mediations. The unstandardized regression coefficients (B) were used in the interpretation of the results. For HIV treatment adherence and autonomy, significant mediators did not emerge.

The mediating effect of intrinsic motivation on the relationship between Internal HLOC and HIV treatment adherence was not supported, as the estimate of the indirect effect was not significant, $B = .01$, 95% CI $[-0.01, 0.05]$, and the relationship between Internal HLOC and CASE Adherence Index was also not significant, $B = .06$, $p = .24$. The remaining paths indicated that Internal HLOC did not have an effect on intrinsic motivation, $B = .47$, $p = .13$. Lastly, intrinsic motivation was not associated with HIV treatment adherence scores, after controlling for Internal HLOC, $B = .02$, $p = .43$, as shown in Figure 3.

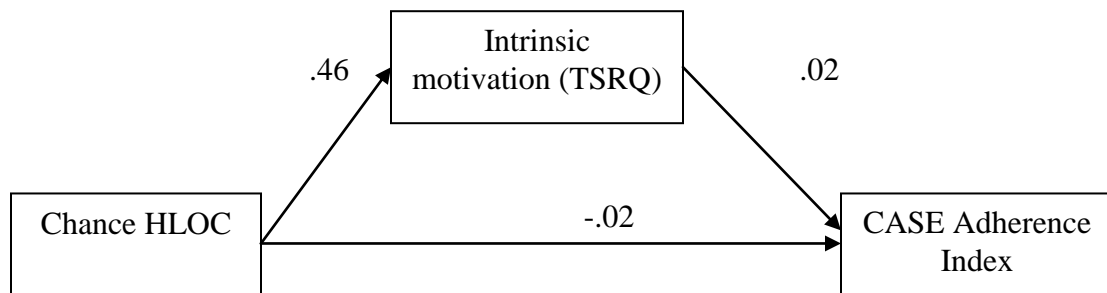
Figure 3. The mediating effect of Intrinsic motivation on the relationship between Internal HLOC and HIV treatment adherence.



The unstandardized regression coefficients are illustrated. This mediation was not supported.

The mediating effect of intrinsic motivation on the relationship between Chance HLOC and HIV treatment adherence is illustrated in Figure 4. This mediation was not supported, as the relationship between Chance HLOC and CASE Adherence Index was not significant, $B = -.02$, $p = .67$, and the estimate of the indirect effect was also not significant, $B = .01$, 95% CI $[-0.02, 0.04]$. The remaining paths indicated that Chance HLOC did not have an effect on intrinsic motivation, $B = .46$, $p = .14$. Lastly, intrinsic motivation was not related to HIV treatment adherence scores, even after controlling for Chance HLOC, $B = -.03$, $p = .59$.

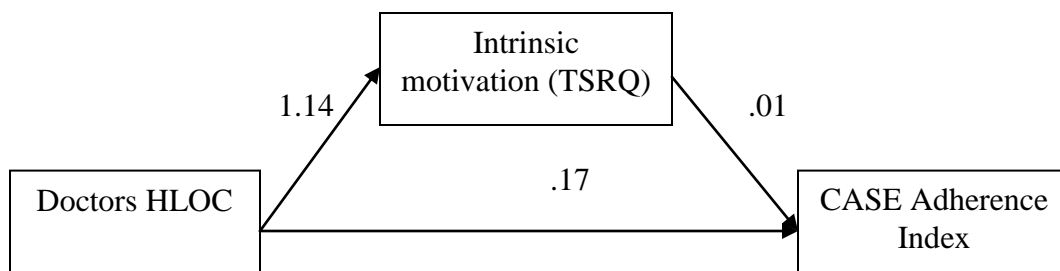
Figure 4. The mediating effect of intrinsic motivation on the relationship between Chance HLOC and HIV treatment adherence



The unstandardized regression coefficients are illustrated. This mediation was not supported.

The mediating effect of intrinsic motivation on the relationship between Doctors HLOC and HIV treatment adherence was not supported (see Figure 5). The relationship between Doctors HLOC and CASE Adherence Index was not significant, $B = .17$, $p = .16$ and, the estimate of the indirect effect was also not significant, $B = .02$, 95% CI [-0.05, 0.13]. The remaining paths indicated that Doctor HLOC had a significant effect on intrinsic motivation, $B = 1.14$, $p = .03$. Lastly, intrinsic motivation was not associated with HIV treatment adherence scores, even after controlling for Doctors HLOC, $B = .01$, $p = .63$.

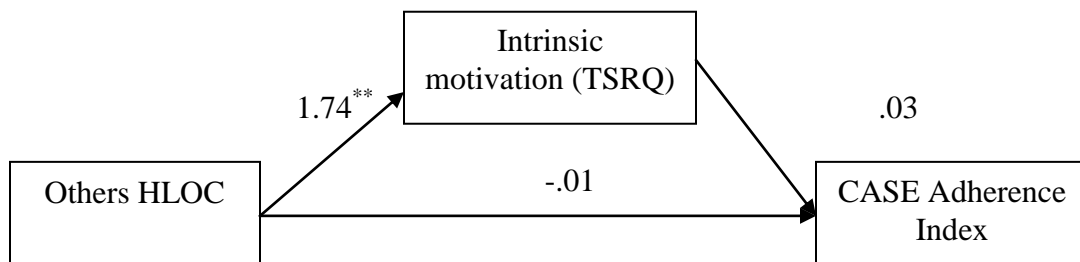
Figure 5. The mediating effect of intrinsic motivation on the relationship between Doctors HLOC and HIV treatment adherence



The unstandardized regression coefficients are illustrated. This mediation was not supported.

The mediating effect of intrinsic motivation on the relationship between Others HLOC and HIV treatment adherence was also not supported. Others HLOC was not significantly associated with HIV treatment adherence, $B = -.01$, $p = .96$. In addition, the bootstrapping results indicated a non-significant estimate of the indirect effect, $B = .05$, 95% CI $[-0.05, 0.17]$. However, Others HLOC and intrinsic motivation were significantly associated, $B = 1.74$, $p = .001$. Lastly, intrinsic motivation was not related to HIV treatment adherence scores, even after accounting for Others HLOC, $B = .03$, $p = .34$. Figure 6 illustrates this mediation analysis.

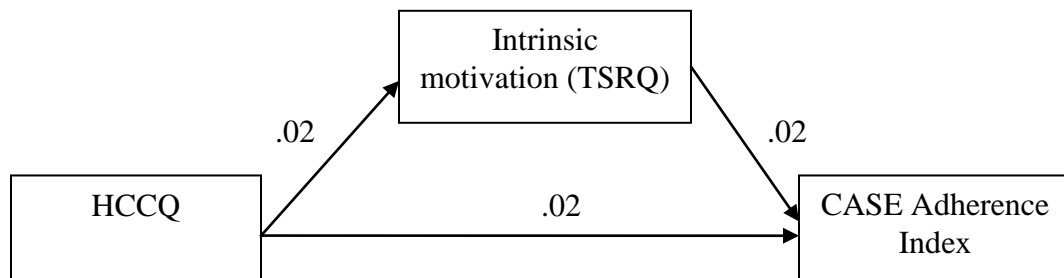
Figure 6. The mediating effect of intrinsic motivation on the relationship between Others HLC and HIV treatment adherence



The unstandardized regression coefficients are illustrated. This mediation was not supported.

The relationship between HCCQ and HIV treatment adherence was not significant, $B = .01$, $p = .35$, and the estimate of the indirect effect was also not significant, $B = .005$, 95% CI $[-0.01, 0.01]$, indicating that intrinsic motivation did not have a mediating effect on the relationship between HCCQ and HIV treatment adherence. HCCQ was also not significantly associated with intrinsic motivation, $B = .02$, $p = .83$. Lastly, intrinsic motivation was not associated with HIV treatment adherence scores, even after controlling for HCCQ, $B = .02$, $p = .40$. Refer to Figure 7 for this mediation.

Figure 7. The mediating effect of intrinsic motivation on the relationship between HCCQ and HIV treatment

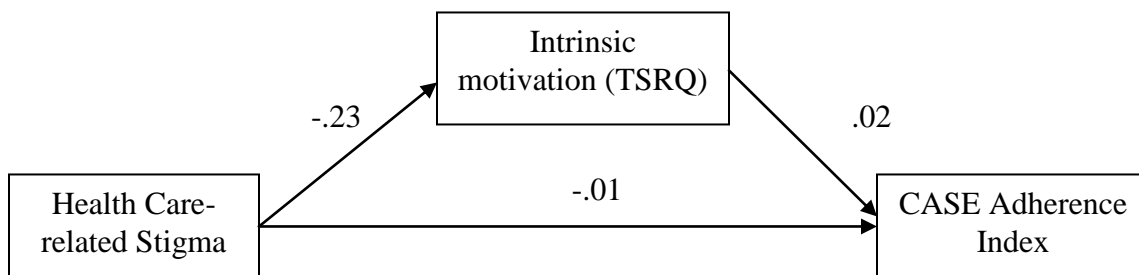


The unstandardized regression coefficients are illustrated. This mediation was not supported.

Hypotheses 2a and 2b stated that intrinsic motivation (TSRQ) would mediate the relationship between *relatedness* (health care-related stigma and social support) and HIV treatment adherence (CASE Adherence Index). Figures 8 and 9 illustrate these mediations. The unstandardized regression coefficients (B) were used in the interpretation of the results. For HIV treatment adherence and relatedness significant mediators did not emerge.

The mediating effect of intrinsic motivation on the relationship between health care-related stigma and HIV treatment adherence was not supported (see Figure 8). Specifically, the estimate of the indirect effect was not statistically significant, $B = -.01$, 95% CI $[-.03, .01]$, and the relationship between health care-related stigma and CASE Adherence Index was also not supported, $B = -.02$, $p = .68$. Health care-related stigma was also not related to intrinsic motivation, $B = -.23$, $p = .30$. Even after controlling for health care-related stigma, intrinsic motivation was not associated with HIV treatment adherence, $B = .02$, $p = .34$.

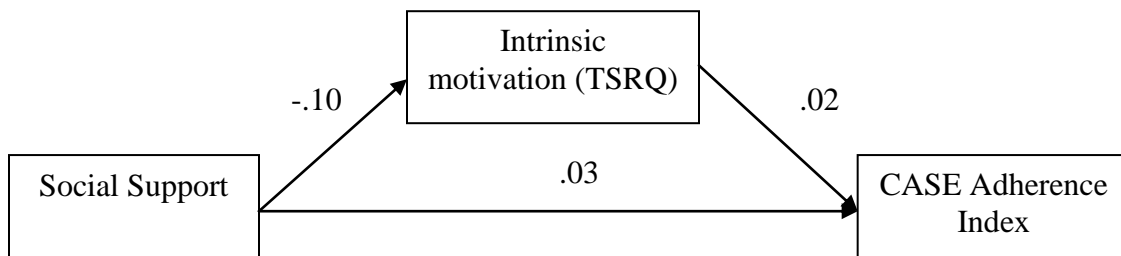
Figure 8. The mediating effect of intrinsic motivation on the relationship between Health Care-related Stigma and HIV treatment adherence (CASE Adherence Index).



The unstandardized regression coefficients are illustrated. This mediation was not supported.

Figure 9 illustrates the mediating effect of intrinsic motivation on the relationship between social support and HIV treatment adherence. This mediation was not supported. The estimate of the indirect effect was not significant $B = -.02$, 95% CI $[-0.06, 0.02]$, and the relationship between social support and HIV treatment adherence was also not significant, $B = .03$, $p = .69$. Intrinsic motivation was not associated with HIV treatment adherence scores, even after controlling for social support, $B = .03$, $p = .30$. The remaining paths indicated that social support did not have an effect on intrinsic motivation, $B = -.10$, $p = .82$.

Figure 9. The mediating effect of intrinsic motivation on the relationship between Social Support and HIV treatment adherence (CASE Adherence Index).

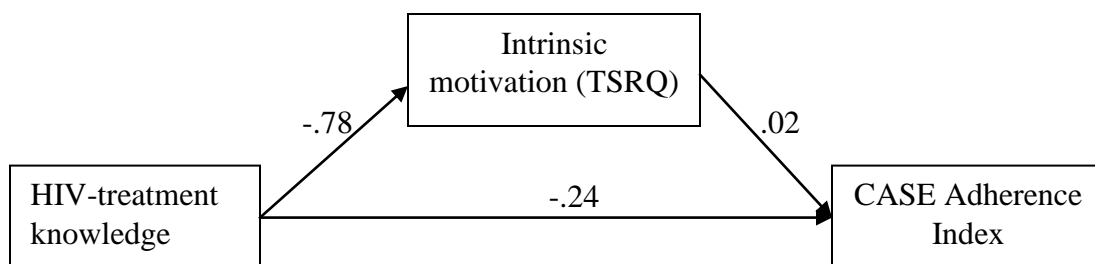


The unstandardized regression coefficients are illustrated. This mediation was not supported.

Hypotheses 3a and 3b stated that intrinsic motivation would mediate the relationship between *competence* (HIV treatment knowledge and HIV-treatment self-efficacy) and HIV treatment adherence. Figures 10 and 11 illustrate these mediations. The unstandardized regression coefficients (B) were used in the interpretation of the findings. For HIV treatment adherence and competence, significant mediators did not emerge.

The mediating effect of intrinsic motivation on the relationship between HIV treatment knowledge and HIV treatment adherence was not supported, as the estimate of the indirect effect was not significant $B = -.02$, 95% CI $[-0.10, 0.05]$. The relationship between HIV treatment knowledge and CASE Adherence Index was also not significant, $B = -.24$, $p = .23$. The remaining paths indicated that HIV treatment knowledge did not have an effect on intrinsic motivation, $B = -.78$, $p = .47$. Lastly, intrinsic motivation was not associated with high HIV treatment adherence scores, even after controlling for HIV treatment knowledge, $B = .02$, $p = .43$. Refer to Figure 10.

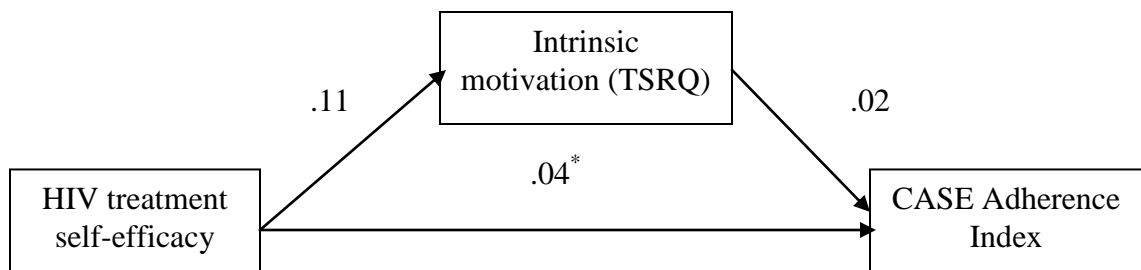
Figure 10. The mediating effect of intrinsic motivation on the relationship between HIV treatment knowledge and HIV-treatment adherence



The unstandardized regression coefficients are illustrated. This mediation was not supported.

The mediating effect of intrinsic motivation on the relationship between HIV treatment self-efficacy and HIV treatment adherence was also not supported because the estimate of the indirect effect was not significant $B = .01$, 95% CI $[-0.01, 0.01]$. This mediation is illustrated in Figure 11. HIV treatment self-efficacy, however, was statistically significant with HIV treatment adherence, $B = .02$, $p = .02$. The remaining paths of this model were not significant. Specifically, HIV treatment self-efficacy was not related to intrinsic motivation, $B = .11$, $p = .18$, and even after controlling for HIV treatment self-efficacy, intrinsic motivation was not associated with HIV treatment adherence scores, $B = .02$, $p = .50$.

Figure 11. The mediating effect of intrinsic motivation on the relationship between HIV treatment self-efficacy and HIV treatment adherence

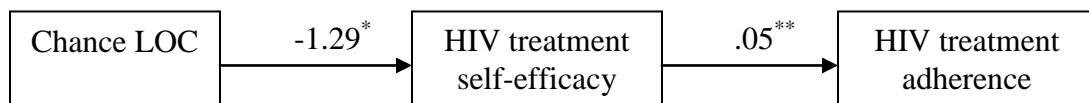


The unstandardized regression coefficients are illustrated. This mediation was not supported.

Ancillary Analyses: HIV Treatment Self-efficacy

The objective of the ancillary analyses was to gain a more comprehensive understanding of the relationship between HIV treatment self-efficacy and HIV treatment adherence. In the Pearson product-moment correlations, HIV treatment self-efficacy was significantly and positively correlated with HIV treatment adherence; therefore, in an aim to further understand this relationship, several ancillary mediation analyses were tested. Particularly, HIV treatment self-efficacy was predicted to be a mediator between the predictor variables, tested as part of the main hypothesis, and HIV treatment adherence. The results indicated only one indirect effect: Chance HLOC significantly predicted HIV treatment self-efficacy, $B = -1.29$, $p = .01$, and in turn HIV treatment self-efficacy was significantly associated with HIV treatment adherence, even after controlling for Chance HLOC, $B = .05$, $p < .001$, and this indirect effect was statistically significant, $B = -.07$, 95% CI $[-0.15, -0.01]$. That is, people who perceived that others had control over their health, had low HIV treatment self-efficacy; however, high scores on the self-efficacy scale was associated with better HIV treatment adherence rates, see Figure 12.

Figure 12. An indirect effect between Chance HLC and HIV treatment adherence, through HIV treatment self-efficacy.



The unstandardized regression (B) coefficients are illustrated. This indirect effect was supported.

Phase II: Semi-structured Interviews (Qualitative Data)

Each interview was audio recorded and transcribed. The transcriptions were read and quotes were extracted that best supported the constructs investigated throughout the present study, that is autonomy (autonomy-supportive physicians and health locus of control), relatedness (social support and stigma), and competence (HIV treatment knowledge and HIV treatment self-efficacy). Ellipsis (...) indicated pauses in the participants' responses.

Descriptive Information of the Participants

Eleven participants were interviewed for the second phase of this study. Seven males and 4 females participated in the face-to-face semi-structured interviews. Three of the participants (2 males and 1 female) were recruited from AIDS Committee of Windsor (Windsor, ON), and the remaining 8 participants (5 males, 3 females) were clients of Fife House Inc. (Toronto, ON). Fife House offers short and long-term housing and it is likely that without the support of this organization, the clients of Fife House would be at risk for being homeless. The majority of the participants interviewed were clients of Fife House and they were a unique subpopulation of PLWH because they required housing, as compared to the clients recruited from AIDS Committee of Windsor and PLWH who may not require housing services. Applying the current findings to other populations of PLWH should be done with caution, as this sample is not representative of the general population of PLWH. This is important to note because clients of organizations that offer housing are likely living on their own, as most housing services provide single rooms which exclude families and even couples. Therefore, it is possible that the participants

recruited from Fife House differed in their social support system as compared to participants not living in such housing organizations, for example.

Demographic description of participants. Participants ranged in age from 30 to 59 years ($M = 37.9$, $SD = 7.7$). Average time since HIV diagnosis for this group was 13.9 years ($SD = 6.8$), and on average, the participants had been on HIV treatment for 10.9 years ($SD = 8.3$).

The HIV Treatment Regimen

Two out of the 11 PLWH interviewed indicated that they sometimes forgot to take their HIV treatment; therefore, Phase II found 18% non-adherence rate among this sample of PLWH. Interviewees were asked to indicate how many HIV-related pills per day they had to take. On average, people indicated that they take 2 pills per day ($SD = 1.09$), once a day. Everyone, with the exception of one person, expressed that their HIV treatment regimen was very easy. The one individual, who found his HIV treatment to be complex and difficult, said the following:

They [the HIV treatment regimen] are really cumbersome to take actually, and it takes a lot of organization because I have to take it a certain time - always, and one of the ARVs [Antiretrovirals] that I take is [sic] - has to be refrigerated - so I can't put it in a blister pack that would make it simpler. (Male, on HIV treatment for 13 years)

This individual indicated that he has to take the HIV treatment four times per day and because the drug needs to be refrigerated, he is bound to be near his home.

Therefore, with the exclusion of one male participant, as a whole, the sample of PLWH in this study expressed that they did not have complicated HIV treatment regimens. Two female participants conveyed throughout the interview that their HIV

treatment schedule had gotten much simpler, as compared to the treatment that they had to take in the initial years of their HIV diagnoses, 20 and 13 years ago.

Importance of adhering to the HIV-treatment regimen. Knowing the importance of adhering to the HIV treatment schedule was clearly acknowledged by all of the participants who took part in these interviews. Specifically, participants' were asked, "*Do you think it's important to adhere to your HIV-treatment regimen?*", and 100% (11 out of 11) people indicated that it is very important to adhere to the prescribed regimen. Therefore, everyone agreed that adhering to the prescribed HIV treatment was important for his or her health and for the effectiveness of the HIV treatment. One participant had the following to say, "Yes it is very, very important [to adhere to the HIV treatment] because I am already resistant to one set of meds, so in order to make sure that I don't build new resistance [sic]." (Male, on HIV treatment for 13 years).

Difficulties adhering to HIV treatment regimen. Participants were then asked if they found adhering to the HIV treatment to be difficult. Three out of the 11 interviewed (27%), all males, expressed that it was difficult for them to adhere to their HIV treatment regimen. On average these three individuals had been on HIV treatment for 7 years ($SD = 6.56$). One of the respondents found it hard because of their complicated HIV treatment regimen.

The second interviewee found the regimen difficult to take because he would forget to take his medication. Specifically, he said, "I have difficulties remembering to take my meds daily. Like when I am supposed to take them, it's like yesterday I forgot, today I took them". When this participant was further prompted he said, "it's just sometimes I look at them, and I am like I don't want to take them." (Male, on HIV

treatment for 10 years). It was unclear, therefore, whether this male participant did not want to take them, or he did not take them because he simply forgot about his HIV treatment schedule. He was asked if he was experiencing any side effects and he shared that he was not.

The third respondent expressed difficulties with adhering to his HIV treatment regimen because of other medical conditions that he also had. Specifically, he stated that he had drug addiction issues and that he had severe depression. As a result, he found that these two conditions interfered with his prescribed HIV treatment schedule. This respondent had the following to say:

I have had some other issues - health wise [he later stated these health issues are drug addiction and depression] that have interfered with the meds ... missed couple of doses... I was always told that if you missed a day or two it's not good because it compromised the immune system. So I would stop after missing a couple of days for you know 4 months and then I would go see him [the family physician] and tell him. (Male, on HIV treatment for 8 years).

As the interview progressed, this participant shared that because of his drug addiction he would sometimes leave the house for days to join friends and do drugs, without taking the HIV treatment with him. Furthermore, he also partially attributed his difficulties with the HIV treatment to the severe depression that he had been experiencing for the past few years. When this respondent was asked whether he felt that his drug addiction and depression influenced his HIV treatment adherence, he firmly agreed, and stated that:

If I run out of them [the HIV treatment medication] I am usually too depressed to go get them from the pharmacy ... The depression really pulled me into some weird places because I am an intelligent man, and I know what I need to do [related to staying healthy and taking the HIV medication], but I was pretty immobilized from it [the depression].

This respondent was aware that it is dangerous for his health to miss doses of his HIV treatment. This participant clearly identified that his drug addiction and depression were barriers to his successful HIV treatment adherence. He articulated throughout the interview that he had repeatedly requested that his family physician, who was also his HIV specialist, refer him to a psychiatrist. The respondent said that his physician would not refer him unless he sorted out his addiction issues. This point is later revisited during a more comprehensive discussion on quality of health care.

Therefore, from the three male interviewees it can be noted that a demanding and complex HIV treatment regimen, forgetting the HIV treatment and co-morbid health conditions could all make the HIV treatment regimen more difficult to comply with. However, for the respondent with the difficult HIV treatment plan, despite the complex regimen, he felt that the regimen did not influence his HIV treatment adherence in a negative way. For the respondent who had difficulties remembering to take his HIV medications on time, it seemed that this difficulty contributed to lack of HIV treatment adherence. Lastly, the participant who indicated that his drug addictions and depression made his HIV treatment difficult, also indicated that this was a contributing factor for his poor HIV treatment adherence.

HIV treatment related side effects. When participants were asked whether they were experiencing any HIV treatment side effects, 36% (2 males and 2 females) of the respondents indicated that they had side effects as a result of the HIV treatment. One participant had the following to say, "Some mornings I'll wake up and I'll throw up, I can't eat. Like I have no appetite ... I can go for days without feeling hungry." (Female, on HIV treatment for 8 years).

People indicated a number of other side effects, such as parts of the body swelling, losing fat in some parts of the body, heart palpitations, nausea, exhaustion, and diarrhea.

People's Perceptions of Autonomy

Health locus of control. At the beginning of each interview, participants were asked whether they thought they had control over their health. This question was asked to better understand the extent to which participants believed that they could exercise control over their health. Eighty percent of the people (8 out of the 10 people) said that they perceived that they had control over their physical health. One person did not fully understand the question, even after they were provided with prompts and explanations of health locus of control. The remaining two individuals (1 male and 1 female) trusted that they had some control over their health, but suggested that their health also depended on their physician, and/or HIV specialist. For example,

I can say that I am in control of my health, because it's my responsibility to take the medication it's my responsibility to report to the doctor when I am sick, but I don't have the control and knowledge on what to take because that is determined by the professionals. (Female, on HIV treatment for 5 years).

This individual further explained that if she was a physician then she would have a lot more control over her health, but because she did not have the medical knowledge, she was limited in her ability to be in full control of her physical health.

Autonomy-supportive physician. Participants were asked if it was important for them to have a doctor who encouraged them to ask questions related to their health, and if it was important for them to be involved, that is to have some control over their HIV treatment. Ten respondents (91%) said that having a doctor who encouraged them to ask question was very important to them. One male participant until recently did not express interest in having a doctor who would encourage him to be more active towards his

health. However, since 2 months prior, he had started to become more interested in his health and wished to be more involved with decisions regarding his treatment, and health in general. He stated the following, "No and I never really have [wanted his doctor to encourage him to ask questions]. So I almost trust what he says ... Although, that has sort of changed recently. I've been a little more interested to see what is happening." (Male, on HIV treatment for 8 years).

When this individual was prompted with the following question: Given that you started to be more interested, does your doctor make the time to answer your questions? This male respondent answered, "No I find him very surface, he is misdiagnosed many times, or he is taken the time [took a long time] to actually diagnose something, elements of something, which sounds like its should've been pretty obvious to me, I feel a little neglected sometimes - yes." Unfortunately, this response was echoed by 3 more people (27%). That is, these respondents also indicated that they did not have an autonomy-supportive physician. Two of these participants stated that they did not spend enough time with their physicians, even when they had scheduled an appointment in advance. For example, "I would like that [to spend more time with my doctor] but the doctor that I have is pretty busy and has a lot of clients, so I do feel little pressed even when I have an appointment with him". (Male, on HIV treatment for 13 years).

The third respondent stated that he did not have a physician who encouraged him to ask questions, but he was also not interested in having such a relationship with his practitioner. This respondent expressed that he had complete trust in his physician's decision concerning his health.

When these individuals were asked if they thought that their physicians' busy schedules influenced their ability to properly take their HIV medication, they indicated that it was not related - If they had questions, they would ask them anyway.

Accounts Related to Relatedness (Social Support and Experienced Health Care-related Stigma).

Participants were asked questions pertaining to their level of perceived social support from family members and friends. In addition, participants were also asked if they perceived that the health care system was free of HIV-related stigma, and whether health care providers were non-judgmental and helpful.

Social support. Due to time constraint two people were not asked whether they had the support of family members and friends. In addition, one man indicated that he has lived on the streets for the past 15 years, and he did not give a clear answer of the extent to which he felt that he had the support of family or friends. From the eight remaining people who answered this question, 4 respondents (3 female and 1 male) stated that they did not have the support from any family member. For instance, one responded shared that,

Actually, my parents have both passed away. Since I found out I told my brother and my family right away, that I was HIV. My brother never spoke to me from that day on. And I tried and until today he will not speak to me. I don't know where he is, what he is doing, and I don't try anymore. (Female, on HIV treatment for 20 years)

Another participant shared that, "not too much of family because I have been away from my family for quite a while." (Male, on HIV treatment for 3 years).

The remaining 4 individuals (1 female and 3 males) indicated that they had social support only from some family members. When asked if having the support of family

members helped with regularly taking the HIV treatment, some indicated that it did help. For example, one male participant shared the following:

She knows [his fiancé] how important it is, you know what I mean. She doesn't want me to see me get sick. I think about it, and I know you don't want me to get sick, so I am going to take my meds. (Male, on HIV treatment for 10 years)

This respondent shared that his fiancé was an effective motivator for him to take his medication daily. In addition, his fiancé often reminded him to take his pills, because he indicated that he was forgetful.

All eight individuals identified that they had some social support either from friends, or from peer support networks (e.g., Hepatitis C co-infected group). Although everyone expressed that they had a support network, generally it had not been easy to disclose their HIV-status to friends. One female participant shared her deep feelings about some of the hurt that she experienced from friends, because of her HIV diagnosis. She said,

You know, who would want this? You know I am still human, I am still me, there is still more to me than I am HIV+, that's just something that happened, you know. I am still smart, I am still funny, I am out going I am a good person to talk to, I am a good listener, there is so many qualities to me but it's just that when people hear HIV, next to my [sic], that's just the first thing that come up, and they forget the [sic], and is tough [started crying]. I have lost so many friends because I have tried to be honest with them, and it's tough, it's tough, I am still the same person, I didn't ask for this. This choice was made for me, you know who would want this? I am sorry [crying]. (Female, on HIV treatment for 6 years).

Although not everyone shared the same experiences, it was clear from the interviews that people had been disappointed, hurt, and lost friendships because of their HIV status.

HIV-stigma in health care settings. Participants were asked the following 2 questions pertaining to health care-related stigma: 1) "Have you experienced any HIV-related stigma, or discrimination, from your family physician, or HIV specialist?" and 2) "Have you experienced any HIV-related stigma, or discrimination, from any other health care provider (i.e., doctors in a hospital, nurses, dentists, any health care-related provider)?"

Perceived stigma from family physicians, or HIV specialists, did not emerge. That is, everyone ($n = 11$) was able to agree that they had never experienced stigma nor discrimination from their general practitioner, and/or their HIV specialist. For instance, one female participant shared the following, "I adore my general practitioner ... my general practitioner is very, very nice and treats me you know as I wasn't HIV-positive." (Female, on HIV treatment for 5 years)

A clear distinction should be made, however: although stigma was not specifically reported, this was not indicative that everyone was completely happy with the services that they received from their family physician, or from their HIV specialists. Some people found their HIV-specialist, or family physician to be non-helpful or arrogant. For instance, "I adore my GP, and I think my HIV specialist is a pompous jackass, but that's a whole another story. He thinks he knows it all". (Female, on HIV treatment for 6 years) Overall, however, people indicated that their family physicians, or HIV specialist, were very supportive, helpful, and non-judgmental towards them.

Regarding perceptions of stigma in health care settings, 6 of the respondents (1 female and 5 males) had very strong reactions against hospital staff, particularly nurses,

and one psychiatrist. A male participant who had a negative experience with a psychiatrist shared this:

I also have psychological problems, so basically I was ... I met the doctor there and she was a relatively new doctor there and the experience that I had ... she wasn't aware that I was HIV+ because I'm also paranoid-schizophrenic and that's why she was seeing me, she was seeing me for mental but she and I shook hands and sat down and then when I told her that I was HIV+ she looked afraid and ran out of the room, and ran to the bathroom - I guess to wash her hands. But it was the way that she reacted to that information that really, really made me feel down on myself. (Male, on HIV treatment for 13 years).

Another respondent was staying at a downtown Toronto hospital because he required a surgery to repair damaged veins in his arm, because of injection drug use. The nurses at the hospital made him feel unworthy, and he had the following to share, "I was treated [in the hospital] like dirt actually. Just a junkie anyway sort of thing. It was really kind of weird, weird thing because it's not what I am anyway." On the positive side, however, he had the following to say, "The doctor [his surgeon] was great though ... He was really good. The other ones were afraid to touch me and it was weird." During the interview, this man was asked to describe a particular experience that he had during his 5-day stay at the hospital, and he shared the following,

You know, I don't know if they meant to but I remember when I was in there ... and my IV kept blocking and this big Middle Eastern nurse would come and say 'it's too bad', and really pound it [the IV needle], it really was to say that's what you get, but it was extremely painful and she really wouldn't care. I was trying to make excuses why it has been this way ... maybe I should stop and why they have not been really helpful" (male, on HIV treatment for 8 years).

This respondent was not only emotionally hurt by being treated like a 'junkie' but also he was physically hurt because of the insensitive health care provision. He has tried to bring a meaning to these negative experiences, by repeatedly stating that he was not sure why he has been treated this way.

On a similar note, another person had the following to say,

They wouldn't do nothing for me. I would say, excuse me can I get a glass of water, they would say 'get it yourself'. I would say 'excuse me', they would say 'shut up, leave me alone'. No they wouldn't do nothing for me. So I would just take off on them all the time. (Male, on HIV-treatment for 20 years)

The respondents brought up other instances related to lack of sensitive health care provision, and another male participant shared the following,

Well... With some doctors or nurses, or whatever the thing is that they associate you with being a junkie or homosexual. You know they, so, they often think that he is going to go and get high, so why should we treat him. Not all of them but that's how I think anyways. You know. (Male, on HIV treatment for more than 25 years).

This respondent also shared that in the 1980s, before people knew what the HIV virus was, it was understandable for people to have been afraid. However, his disappointment with the health care system stemmed from the fact that today we know a lot more about the HIV virus and there is no excuse for people to be rude, judgmental, and discriminatory.

An instance of discrimination and lack of health care provision was shared by another male participant. This person was admitted to a downtown Toronto hospital because he needed abdominal surgery. He shared that he did not receive proper care at the hospital, because he was not given his HIV medication. Typically, surgical procedures suppress the immune system (Newsholme, 2001), making it easier to get an infection, or have other complications; thus, it is crucial for PLWH not to miss their HIV treatment during such medical procedures. Therefore, because of the importance of this issue he was deeply disturbed by the lack of actions to supply his medication, on the part of the health care providers. He said,

They [the nurses] gave me my medication for one day, and then the next day they said 'we ran out, we only have 1 pill', so 1 out of the three, because it is combination therapy that is necessary and it's not just one - but they gave me one pill. ... I don't know what was in the mind of the doctor, or whoever was in control of that, but it really hurt me a lot because I was in a vulnerable position anyway. Because I don't have any family here and basically I didn't have anybody to visit me, to overlook anything, so I was at the mercy of the doctors and the nurses. So basically I felt very vulnerable and I recovered very quickly from the exploratory surgery just to leave. (Male, on HIV treatment for 13 years)

Another perspective on health care-related stigma was brought in by a female participant, raising an issue related to lack of sensitivity and ignorance among some of the hospital staff. She said,

I think nurses need a sensitivity training where people with HIV are concerned. For example, when I was pregnant, I needed to go to an OBGYN triage because I thought I was going into labour prematurely, and the nurse there looked at my chart and said 'How dare I bring a child into this world?', being that I am HIV+. And I looked at her and said 'how dare you to work in this department, and not know that you have better chances of going and sleeping with somebody and stand and contract HIV, than I do giving it to my child. Did you know that there's a 0.02% chance of transmission, from a mother to a child, during labour and only during labour?' (Female, on HIV treatment for 8 years)

This participant slightly understated the risk of HIV vertical transmission (i.e., mother to a child transmission). In the literature the approximate risk for mother to child transmission (MTC) is reported to be less than 2% and this percentage is true if the mother started treatment in the early stages of her pregnancy, and it also depends on the mother's health at the time of her pregnancy (Cooper et al., 2002). This participant was also incorrect to say that mother-to-child transmission can only occur during labour. In fact, the HIV virus can be transmitted to the baby during pregnancy and breastfeeding as well. Nevertheless, this was an important quote as it captured the negative health care related experiences that this woman has had because of her pregnancy. She continued the conversation by sharing the following,

So they make you feel like you are nothing, like you are worthless, they stigmatize you like in front of you. Like you know, hey [a lab technician would say to another lab technician] 'can you give me those AIDS gloves' [meaning double gloves], I don't need everyone to know that I am HIV+, I am very private and I would like to keep it that way.

On the other hand, some participants indicated a better outlook on the health care system. Five respondents did not have anything negative to comment about concerning their experiences with hospital staff or any other health care provider. Out of these 5 participants, 2 respondents (1 male and 1 female) do not go to hospitals because they are unhappy with the long wait times, and thus they prefer to wait until their family physician, or HIV specialist can attend them. One participant had health care-related stigma experiences as a result of his mental health disorder, but never as a result of his HIV status. Lastly, it was very encouraging to hear that the fifth female respondent, who had been living with HIV for 13 years, had never had a negative experience with hospital health care staff, dentists, nor pharmacists. Specifically, she had the following to say, "I've never experienced that yet ... thank God. But I am hoping that they don't do that kind of thing." (Female, on HIV treatment for 7 months)

HIV-related stigma, unfortunately, exists but it was very encouraging to hear that of the 9 people who attended hospitals (out of the 11 interviewed), 3 of these participants had never experienced stigma or discrimination in health care settings. The 6 respondents who had experienced stigma were further asked if these negative experiences stopped them from going to the hospital and obtaining health care, or if they felt that the lack of health services had an influence on their HIV treatment regimen. The general response was that it did not affect them. For instance,

To be honest ... I am prepared. It doesn't dissuade me from going to the hospital. All the stigma is basically other people's problem ... not my problem, so I just let

it pass over my head and focus on the, what I want in the moment. (Male, on HIV treatment for 13 years)

Despite the considerable anecdotal evidence of HIV-related stigma in health care settings, it was encouraging to hear that some of the participants were not compromising their health by avoiding health care services, in order to avoid the stigma and discrimination that evidently exists.

Themes Related to Competence

The questions on competence were concerned with factors that may influence HIV treatment adherence, such as general knowledge related to the HIV treatment and perceived ability to be able to adhere to the HIV treatment despite obstacles.

HIV treatment Knowledge. Specifically, the following question was asked in an attempt to gauge the participants' knowledge of how their HIV treatment works: "When your viral load is undetectable do you stop using your HIV medications?" Two people were not asked this question because the interview was approaching one hour in length. From the 9 people asked, 8 people firmly disagreed with the question, and indicated that they would not take a break from their HIV treatment based on their HIV viral load. One interviewee said,

No. Yeah I am undetectable right now with the HIV and I am undetectable with the Hep C, so as long as I keep taking the meds - I'll probably live for a long time. More than what I would've if I didn't start this treatment. (Male, on HIV treatment for 3 years)

Lastly, the one respondent who did not firmly disagree with the questions said, "Well it's up to my doctor" (female, on HIV treatment for 7 months)

Based on the responses to the HIV treatment knowledge question, majority of the respondents were aware that HIV treatment medication breaks do not depend on their health status.

Self-efficacy to adhere to the HIV treatment. Participants were also asked to share whether they perceived themselves to be able to adhere to their HIV treatment schedule even if it was interfering with their daily activities. The majority of the participants indicated that they did not allow their daily activities to interfere with their HIV treatment regimen. All of the participants (11 out of 11) interviewed stated that they took their pills despite their daily schedule. Out of the 11, 8 said that their treatment did not interfere with their schedule at all, because they take the pills first thing in the morning. Conversely, 3 participants (out of the 11), indicated that the treatment did interfere with their daily schedule, but that they took the medication anyway. Specifically, one male participant shared, "They interfere with my daily schedule, because there have been times when the pills feel almost like a hot flash. And you just want to puke, especially when you get too stressed out, and there is a lot stress. (Male, on HIV treatment for 3 years)

A male and a female respondent also said that the medication side effects interfered with their daily schedule. For the male participant, however, his health was a priority and he indicated that he was adherent to his treatment schedule in order to stay healthy, because his CD4 cell count was very low. The female participant, on the other hand, indicated that her children were a priority, above all her other daily activities, and in order to stay healthy for her children she adhered to her prescribed HIV treatment regimen.

Additional Themes that Emerged

Treating co-morbidities. Although participants were not asked whether they had additional medical diagnoses, a few indicated multiple medical health conditions, in addition to their HIV-positive status. Specifically, 1 male participant felt that it was important for him to share that he had been diagnosed with Hepatitis C and depression, 1 male participant indicated Hepatitis C, and lastly another male participant shared that he had rapid-cycling bipolar.

When the participant diagnosed with Hepatitis C was asked if he received proper care for his co-existing conditions, he said,

It's a whole team of doctors constantly monitoring. They constantly [sic] ... if you are open to them and you are showing that you want to be involved with your health care they are going to be just as receptive and just as caring. (Male, on HIV treatment for 3 years)

It was very encouraging to hear that some people were getting the required treatment that they needed and deserved.

Conversely, the male participant diagnosed with Hepatitis C and depression, shared that his health care treatment had been very negative. This individual shared the following,

It took him [his physician] 3-4 months with the blood work to figure out that I have Hep C first of all. And the treatment actually causes - the Interferon injection that I have to do once a week causes severe depression and he knew I was susceptible. And even after I was treated and you know went to and I cried in my bed ... I only did 3 months out of a 9 month treatment that was proposed for me. (Male, on HIV treatment for 8 years)

This participant continued the conversation and said the following:

This was 2 years ago. I was in my bed curled up crying for the next 3 months before I went to the doctor and I said 'I guess I gotta [sic] get back on, I messed up, I couldn't do it'. And he goes [his physician] and he even said 'maybe we should've put you on depression pills before you started since Interferon [the

Hepatitis C treatment] causes severe depression'. So he missed a lot of things along the way like he is not really ... I am just like a number almost. It just really odd and you know the thing with Hepatitis C is that your liver enzymes are huge, and mine were 3 times in a row and they went back to normal and they went huge again. So he couldn't figure out that it was my body trying to fight it - apparently 20% of the people that contract it don't really know because you can actually fight it yourself ... like why wouldn't you tell me this before. Whether I wanted to or not [to hear about medical related issues] ... stuff like that. The depression pills he should've know that for sure. Since 2001 I've been on depression pills really. (Male, on HIV treatment for 8 years)

Unfortunately, this person's Hepatitis C diagnosis took a long time to be identified. The treatment for the Hepatitis C had long-term and very damaging effects on this person.

For example, this participant cried for days from the severe depression and without the support of any health care providers.

For the male participant diagnosed with rapid cycling bipolar, he indicated that he had also been diagnosed with a series of other physical health conditions because of being severely physically abused by his former partner. This person had knee and hip replacement surgery, and also as a result of the assault both of his ankles were shattered. This individual took 18 pills in the morning, 10 in the afternoon, and 14 at bedtime and only 2 pills were for his HIV. When he was asked if he is receiving proper care for his medical conditions, he stated the following:

Yes ... Yeah I don't have a regular psychologist [maybe he meant psychiatrist] that I see, but I do have one that I have been dealing with for the last 5 years, through my family doctor. And he has no room to take patients on a permanent basis but if it comes to a point where we need to adjust my medication, or I am in a crisis stage, he will take me on and see me for 3 months or 6 months, once or twice a week if I need it. (Male, on HIV treatment for 3 years)

Therefore, of the 3 individuals who shared that they had additional medical diagnoses, only 1 individual seemed to be receiving comprehensive health care for his co-infection (Hepatitis C and HIV). The individual diagnosed with rapid cycling bipolar

was receiving care; however, in order to receive care his mental health state had to become critical. Lastly, it was evident that the third respondent was in need of mental health services, and needed a treatment support program to help with overcoming his drug addiction. At the time of the interview, this individual was still not receiving the care that he required for his multiple health conditions.

Coping with HIV. Three participants alluded to their HIV-related coping strategies. Specifically, 2 female participants and 1 male shared a similar theme of coping with HIV by ignoring their HIV positive status. One female participant shared the following, "Half of the time I don't think that I am HIV, so I don't play on the fact that I am sick, that I have AIDS or HIV, to me it's the same thing - I don't know why they break it down." (Female, on HIV treatment for 20 years).

Similarly, another female participant said,

I like to think it [the HIV virus] as flu that will not go away. It's easier mentally for me to find a way of accepting it, because I tested positive at 17 after my first sexual encounter. So just to carry that burden for 8 years, I finally had to come to a realization hey this is not a bad dream this is reality. (Female, on HIV medication for 6 years)

The male participant shared that, "There was a sort of the denial thing for the longest time so if I leave them at home ... it's hard to say. There were few issues but I really did need a psychiatrist and I still think that I do." (Male, on HIV medication for 7 years)

Avoiding the HIV diagnosis, and renaming it to mean "just a bad flu that won't go away", or choosing to forget that they have an HIV diagnosis was one coping related strategy that emerged from some of the interviews.

Other individuals indicated that they were very private about their HIV status; that is, they did not disclose their diagnosis to many people. Perhaps as a way to avoid

rejection and cope with the HIV-positive diagnosis, these individuals chose not to talk about their HIV-status with other people, or only share their health condition with a few selected individuals. Thus, it seemed that for the people interviewed in the current study, these two personal coping strategies (denying the diagnosis or being very private) were ways to cope with the disease and perhaps avoid HIV-related stigma by not disclosing their HIV-status to everyone.

In summary, the responses from the interviews elucidated the experiences of people living with HIV and their HIV treatment regimens. The interviews support the idea that multiple psychosocial factors can influence HIV treatment adherence rates. All of the individuals indicated that it was important to have an autonomy-supportive physician, one who encouraged their patients to ask questions, and took actions to better their health. However, the anecdotal evidence showed that over one third of the individuals did not have such optimal health care. Furthermore, health care providers (especially as part of large hospitals) were sometimes judgmental, discriminatory and unhelpful towards patients diagnosed with HIV. People also indicated that a number of HIV treatment side effects could sometimes interfere with their daily activities. Other challenges that were indicated, that made the HIV treatment more difficult to adhere to, were additional medical diagnoses, such as depression. However, despite these multiple challenges faced by these participants, the majority indicated that they were adherent to their prescribed HIV treatment regimen. Some participants found means to overcome these difficulties by focusing on the importance of their health, that is keeping their CD4 cell count high and their HIV-viral load low. A few people indicated that their health was a number one priority because their loved ones (romantic partners or children) gave

them the strength to persevere with the side effects, and to continue taking their HIV medication. The findings from these semi-structured face-to-face interviews highlighted the importance of autonomy, HIV treatment self-efficacy, social support, medical health co-morbidities, and HIV treatment side effects, as important variables that help to understand the complexities associated with HIV treatment adherence.

CHAPTER IV

DISCUSSION

Consistent adherence to HIV treatment regimens is necessary to achieve the maximum benefit of the medication and to reduce the risk of HIV resistance to the medication (Catz, Kelly, Bogart, Benotsch, & McAuliffe, 2000). The present study sought to understand psychological and social factors that influence HIV treatment adherence in a sample of people living with HIV (PLWH); Self-Determination Theory (SDT; Deci & Ryan, 1985) guided this study. Specifically, the aim of the study was to examine the relationship between autonomy (autonomy-supportive physicians and health locus of control), relatedness (perceived social support and HIV-related stigma in health care settings), and competence (HIV treatment knowledge and HIV treatment self-efficacy) and HIV treatment adherence.

The study had two phases: Phase I used self-report questionnaires to assess predictors of HIV treatment adherence, and Phase II used face-to-face semi-structured interviews to gain in-depth understanding of people's experiences taking and adhering to the HIV treatment regimen. The quantitative and the qualitative data uniquely contributed to revealing aspects about people's experiences with their HIV treatment regimens.

Summary of Findings

In Phase I, none of the main hypothesized mediating relationships were supported. Mediation analyses did not find support for *autonomy*, one of the three main constructs of Self-Determination Theory (SDT). Bivariate correlational analysis, however, showed that Doctors HLOC and having an autonomy-supportive physician (HCCQ) were related

to higher HIV treatment adherence. Phase II supported the important role of the primary health care physician; specifically, respondents reported that their physician was a source of knowledge and power to prescribe the HIV medication.

The second construct as part of SDT - *relatedness* - was also not statistically related to HIV treatment adherence, as assessed by the hypothesized mediations. In Phase II, anecdotal evidence indicated that for the participants who had the support of family members, their loved ones were an important motivator related to HIV treatment adherence. Unfortunately, half of the people interviewed in Phase II indicated that they did not have contact with any family members. In Phase I and II, HIV-related stigma in health care settings was not associated with HIV treatment adherence.

Lastly, the third construct as part of SDT - *competence* - was also not associated with HIV treatment adherence, as assessed by the hypothesized mediations. However, simple Pearson product moment correlations showed that HIV treatment self-efficacy was significantly related to HIV treatment adherence.

Therefore, in summary, Phase I results revealed several significant bivariate correlations. Specifically, it was found that older age, having autonomy-supportive physicians (HCCQ), high Health Locus of Control for Doctors (i.e., Doctors HLOC) and high HIV treatment self-efficacy (HIV-ASES), were all associated with successful HIV treatment adherence. On the other hand, HIV treatment side effects, specifically headache, were found to be a barrier to successful adherence. Lastly, post-hoc analysis revealed that HIV treatment self-efficacy mediated the relationship between Chance HLOC and HIV treatment adherence.

In Phase II, participants shared their perceived challenges associated with taking the HIV medications. The most frequent response associated with making the HIV treatment difficult to adhere to was the side effects (e.g., vomiting, diarrhea, weakness, body fat redistribution, etc). Co-morbidities also surfaced as an additional challenge; for example, people diagnosed with depression and HIV, or other mental health conditions, indicated some difficulties with successfully taking their HIV medication. Lack of consistent and proper health care provision additionally complicates these co-morbidities. Conversely, some of the buffers identified in Phase II were the support of a family member, and a strong desire to be healthy. Finally, it was found that ignoring the illness, and keeping the diagnosis as private as possible were common coping strategies associated with HIV in the present study.

Rate of HIV Treatment Adherence

Based on the CASE Adherence Index results, in Phase I, two-fifths of the sample (41.8%) was classified as having poor HIV treatment adherence (CASE Adherence Index ≤ 10). The high prevalence of poor HIV treatment adherence in this sample of PLWH is consistent with other research (e.g., Gordillo et al., 1999). For example, Gordillo and colleagues (1999) found that 42% of the mixed-gendered sample of PLWH in their study self-reported being non-adherent. In general, however, the published findings on HIV treatment adherence rates vary widely. This is mostly because of the multiple ways in which HIV treatment adherence can be measured. Most often authors report adherence as a dichotomous variable, which has a cut-off value of 95% ($< 95\%$ is non-adherence). Ninety-five percent is often used because it is considered an optimal cut-off criterion for immune functioning; that is, people who are adherent less than 95% of the time have

worse physiological outcomes (Paterson et al., 2000). Based on this criterion, estimates of non-adherence are between 24.2% (Barclay et al., 2007) and 43% (Wenger et al., 1999). Moreover, using a digital monitoring pill count, the HIV treatment adherence rates become even more variable, ranging from 25.3% (Paterson et al., 2000) to 62% (Bangsberg et al., 2000). Therefore, although the rates for HIV treatment adherence vary in the published literature, the 42% non-adherence rate found in the present study was similar to the self-reported rates found in the general literature.

The Sample of PLWH in the Present Study

The sample of PLWH who took part in Phase I and II of the present study were predominantly males (73.5%), and 57% of the males identified as gay/homosexual. These percentages represent the overall prevalence of males with HIV in Canada. As of 2009, approximately 76% of all HIV cases were males, and the majority identified as gay/homosexual (60%). In terms of ethnicity, however, the sample of PLWH in this study was less diverse, as compared to the Canadian HIV-positive population. In Phase I, the majority of the participants (32%) indicated British/Irish, or Mediterranean descent, 19% were of Southeast Asian descent, 7% were of South Asian background, and 11% were of African or African-Caribbean descent, and small minorities (7%) of participants were of Aboriginal background; lastly, the remaining participants (15%) indicated other or "don't know". The ethnic distribution of PLWH in Canada is more diverse, as compared to the present study, with recent data showing that 44% of PLWH are White, 33% Aboriginal, and 12% Black PLWH (PHAC, 2009). In terms of age, the mean age of participants was 43, and people ranged from 24 to 64 years of age. According to the Public Health Agency of Canada, the highest proportion of HIV case reports is among

people between the ages of 30 to 49 years of age (PHAC, 2009). An interesting finding from Phase I of the present study was that older age was significantly associated with better HIV treatment adherence; this finding is consistent with other published research (Barclay et al., 2007; Kennedy et al., 2004; Paterson et al, 2000). Barclay and colleagues (2007) found that older adults (>50 years of age) were two times more likely to be adherent, as compared to younger participants.

Therefore, in terms of the age, gender, and sexual orientation the demographic distribution of the participants in the present study resembles the demographic characteristics of PLWH in Canada. The ethnic breakdown of the study participants, however, was less representative of the ethnic distribution of PLWH in Canada.

It is very important to note, however, that the participants in this study were exclusively recruited through AIDS Service Organizations (ASOs), which indicates that PLWH not in contact with such service organizations were not included in the present study. Therefore, the sample of PLWH in this study represented a unique subpopulation of PLWH because they were connected with support services (e.g., ASOs), they were literate (Phase I), or were able to understand and speak English (Phase II), and were likely eager to participate because they noticed the posted flyers advertising the study and were interested in taking part in this research. Also, the social and psychological needs of people attending ASOs might be different from the PLWH not in touch with service organizations, and caution should be used when interpreting the findings, in that they should not be generalized to all PLWH.

Furthermore, the subsample of PLWH who participated in Phase I and II also differed. Specifically, the PLWH who participated in Phase II were primarily recruited

from Fife House (64% of the participants), an organization that provides short and long term housing services to people without current homes, and without this organization the people would likely be at risk for being homeless, as compared to the majority of the participants in Phase I, who had their own homes. Typically, housing services for PLWH consist of single rooms and usually families or mothers with children are not housed at these organizations. This is likely why the majority of the participants in Phase II were males. In Phase I, only 31% of the participants were recruited from an organization that offers housing services (McKewan Housing and Support Services). Therefore, in contrast to Phase II, the majority of the participants in Phase I were probably living in their own homes or with family members, or friends. These differences were relevant because the findings from Phase I and II were triangulated. That is, caution was exercised when the findings from Phase I and II were compared, as the degree of overlap between some of the variables (e.g., social support) may have been questionable. Overall, the results from the present study are not intended to be generalized to PLWH beyond this study, especially to other ethnic and racial groups of PLWH not identified in the present sample.

The HIV Treatment Regimen: Complexity and Side Effects

According to some previous findings, one of the key reasons for poor HIV treatment adherence results from the complexity of the regimen; that is, too many pills, dosing frequency, or food restrictions (Ammassari et al., 2002; Corsonello et al., 2009). The present study did not support these findings. In Phase I, specifically, Pearson product-moment correlational analyses did not find an association between number of pills a person needs to consume every day and HIV treatment adherence. There are

several possible reasons that may ultimately help to explain the lack of association between HIV treatment requirements and adherence. In Phase I, the majority of the participants identified that their HIV treatment regimen did not involve taking multiple pills each day. The overwhelming majority (91%) of the participants from Phase II confirmed that they had very simple HIV regimens, consisting of approximately 2 pills per day, and twice a day intake. As a result of this little variability in the number of pills that PLWH had to consume, it was unlikely to find a meaningful statistical association between the HIV treatment regimen and other variables. Therefore, it is possible that the sample of PLWH in this study, had simpler HIV treatment regimens, as compared to the PLWH in other published research. In fact, several of the participants who have been HIV-positive for more than 15 years indicated that in the initial years of the HIV epidemic, the treatments were onerous, but now they were much simpler. Therefore, it could be that HIV treatment complexity and HIV treatment adherence are related but because this sample of PLWH had very simple regimens, this relationship may not have been accurately assessed.

Instead of treatment complexity, what was found to be associated with making the HIV treatment difficult was the resulting HIV treatment side effects. Specifically, in Phase II, approximately half of the participants identified HIV treatment side effects to be very burdensome. However, when the participants were further prompted to share if they thought that their treatment related side effects *interfered* with their HIV treatment adherence, everyone firmly disagreed. All of the participants indicated that they never missed their HIV treatment despite the difficult side effects. Some of the side effects identified by participants in Phase II were diarrhea, vomiting, loss of energy, body fat

redistribution, heart palpitations, nausea, and parts of the body swelling. In Phase I, statistical analysis found that headache symptom severity was significantly associated with poor HIV treatment adherence, while the remaining HIV treatment side effects were not associated with adherence. In addition, 82% of the participants identified weakness (fatigue) as the most *common* side effect. Therefore, it seems that both groups (Phase I and II) were experiencing HIV treatment side effects, but only for the participants in Phase I did these side effects significantly interfere with their treatment adherence. Phase II participants indicated that the side effects made the HIV treatment difficult but these experiences did not interfere with the regimen.

It was unclear why the HIV treatment side effects were more burdensome for participants in Phase I, as compared to Phase II. Perhaps because the participants in Phase II did not report headache-related side effects, they were able to adhere to the treatment despite the other symptoms reported. In addition, social desirability bias may have influenced the interviewees' responses; that is, the participants may not have been comfortable admitting that they were not fully adherent.

In summary, the number of pills that PLWH had to take each day was not found to be associated with poor HIV treatment adherence, but the sample of PLWH in this study tended to have fairly simple treatment regimens. However, Phase I found support for an association between HIV treatment side effects and non-adherence. Phase II did not support the aforementioned results, but the participants in Phase II mentioned that some of the side effects made the HIV treatment regimen more burdensome.

The Main Mediation Findings

The main mediational hypotheses as part of Phase I of the present study were not statistically supported. Possibly a larger sample size would have resulted in significant results.

Autonomy

In the literature, autonomy is typically operationalized as people's perceived control over their environment. In the present study, autonomy was examined in the context of people's perceived ability to have control over their health. In assessing autonomy, participants were asked to indicate if they felt that they had open communication with their physician (i.e., autonomy-supportive physician), where they could exercise some control over their health. Autonomy was further defined as people's perceived ability to influence their health, usually referred to as health locus of control. None of the hypotheses related to autonomy was supported.

Autonomy-supportive physician (HCCQ). It was predicted that an autonomy-supportive physician would be associated with higher motivation to adhere to the HIV treatment, and as a result, this would be associated with better adherence rates. This mediation was not supported. Other researchers, however, have found support for this relationship (Williams et al., 1998). Two reasons could be associated with these contradictory findings. Firstly, Williams and colleagues (1998) had a larger sample size; specifically, 126 PLWH participated in their study. Secondly, Williams and colleagues' (1998) study used two different methods of calculating adherence rates: self-report and prospective pill count at two different time points. Together, these two different methods of assessing HIV treatment adherence represent a less unbiased estimation of the

adherence rates, as compared to the self-report method used in the present study. In Phase I, adherence rates were self-reported and participants may have been reluctant to indicate the frequency of their actual missed doses of the HIV treatment. The adherence rates found in Phase I and in the Williams and colleagues' (1998) study, therefore, may not be comparable because of the different measures utilized to assess adherence. If the present study had used a digit monitoring pill count, for example, a more unbiased method of measuring adherence rates, then perhaps autonomy could have emerged as a predictor of adherence in this sample of PLWH. Therefore, in contrast to the previous literature, the mediation analysis did not find support for the relationship among autonomy-supportive physician, intrinsic motivation, and increased HIV treatment adherence.

Pearson product-moment correlations, however, found some support for the relation between having an *autonomy-supportive physician* and *HIV treatment adherence*. That is, people who had autonomy-supportive physicians had higher adherence rates. This finding is not unique to the present study (e.g., Schneider, Kaplan, Greenfield, Li, & Wilson, 2004). For example, in a mixed gendered sample of 554 PLWH from the United States, researchers found that individuals who perceived that they had more autonomy-supportive physicians had better HIV treatment adherence rates (Schneider et al., 2004). This finding could have important implications for developing interventions aimed to improve adherence rates. Adherence rates among PLWH are generally not high (Bangsberg et al., 2000; Gordillo, Amo, Soriano, & Gonzalez-Lahoz, 1999); thus, when research identifies variables that are associated with better adherence, and these factors are modifiable, then health care providers should adopt them in an effort to help their

patients (Bangsberg et al., 2000). Communication patterns between physicians and patients are modifiable; that is, it is possible for clinicians to become more patient-centered and thus autonomous in their practice (Moral, Alamo, Jurado, & de Torres, 2001), and there is evidence that these training programs can have long-term outcomes (Bowman, Goldberg, Millar, Gask, & McGrath, 1992). Schneider and colleagues (2004), however, pointed out that research is needed to better understand if improved physician-patient communication style through training programs is associated with improved HIV treatment adherence. This could be a future extension and direction of this research.

Pearson product-moment correlations further found some support for the relation between having an autonomy-supportive physician and less psychological distress as reported by the patient. Specifically, high perceptions of having an *autonomy-supportive physician* were correlated with lower *anxiety and depression symptoms*. These findings are congruent with the general literature. For example, in cancer research, better communication style and more autonomy allows the physician to reduce the patient's mental distress (Molleman et al., 1984). Unfortunately, research on autonomy-supportive health care providers and mental health among PLWH is not yet available. This is the first study to find an association between having an autonomy-supportive physician and lower anxiety and depression symptoms. Future research should further examine these relationships.

Autonomy-supportive physician was also statistically correlated with *HIV-related stigma in health care settings*. Specifically, Phase I indicated that patients who perceived that they had an autonomy-supportive physician showed decreased level of HIV-related stigma and discrimination in health care settings. The present study was the first to find

an association between HIV-related stigma in health care settings and having an autonomy-supportive physician. The findings from Phase II were in support of this association. The interviewees who indicated that they had an autonomy-supportive physician indicated fewer instances of perceived stigma from health care settings. One explanation that helped to elucidate this relationship was that the patients who had a good relationship with their physician might have visited hospitals considerably less.

Participants from Phase II generally identified that hospitals (negative stigma-related experiences from dentists were not mentioned) were associated with higher HIV-related stigma and discrimination, as compared to primary health care settings. Other researchers have also supported this view. In the United Kingdom, for example, almost half (49.6%) of the participants sampled identified that they had experienced stigma from a health care worker including their dentist, as compared to only 17.4% of people who reported HIV-related experiences of stigma in primary health care settings (Elford, Ibrahim, Bukutu, & Anderson, 2008). Research suggests that lower levels of education may be associated with discriminatory attitudes toward PLWH (Elford et al., 2008). Moreover, health care providers who are familiar with the appropriate medical procedures when treating patients with infectious diseases are likely less to discriminate (Li et al., 2007). Therefore, one reason for the higher prevalence of HIV-related stigma in health care settings may be because the hospital staff varied in their education levels and in their preparedness to work with patients who have HIV/AIDS (Li et al., 2007). Research suggest that providing HIV/AIDS training increases health care practitioners' knowledge about HIV/AIDS and improves their attitudes toward PLWH (Wu et al., 2002). Primary health care settings, therefore, which specialize in HIV care, have likely

acquired the necessary knowledge, skills, and awareness on how to treat PLWH, and thus a combination of these factors may result in lower HIV-related stigma and discrimination.

Simple Pearson product-moment correlations further revealed that an *autonomy-supportive physician* was also positively associated with *Doctors health locus of control* (Doctors HLOC). That is, participants who perceived that their physician had control over their health (Doctors HLOC) also perceived themselves to have more autonomy from that physician. This is a positive finding, as it indicated that the patient and the physician shared responsibility over the health of the patient. This finding is also consistent with the literature, which suggests that over 80% of PLWH desire to have a balanced and shared responsibility for their health (Deber, Kraetschmer, Urowitz, & Sharpe, 2007). A large meta-analysis study showed that the need for shared decision making is true across patients of most medical conditions, such as in cardiac patients (66%), HIV (81%), and 44% breast cancer patients (Deber et al., 2007). Findings from Phase II supported this desire for shared responsibility. In Phase II, all of the participants indicated that having an autonomy supportive physician was very important for them. Specifically, a common theme that emerged was that they would prefer that their physician listen to them more. This may be because of the nature of the HIV condition, which continues to be a stigmatizing health condition. PLWH may have a limited number of people with whom they can discuss their health concerns, and for many, the family physician or HIV specialist may be that key person. In fact, Pearson correlations revealed that people who have support from their physicians perceived a stronger social support system.

Unfortunately, although everyone desired a little more autonomy from their physician, it was found that one third of the respondents reported that they did not have an autonomy-supportive physician. When the participants, as part of Phase II, were asked if they thought that the lack of autonomy was a barrier to successful HIV treatment adherence, the majority of the respondents indicated that it was not. When further prompted, most participants indicated that if they had a question regarding their treatment or health, they would ask their doctor directly. It was encouraging to hear that participants did not allow themselves to be at the mercy of their physician, and that they took a proactive stance towards their health by asking questions. This is not unique to the participants of this study; in fact, research shows that 94% of HIV-positive patients ask their health care providers questions related to their treatment and health (Catz, Kelly, Bogart, Benotsch, & McAuliffe, 2000). Catz and colleagues (2000) identified this to be a frequently endorsed strategy used to self-promote adherence.

In sum, Phase I bivariate correlations indicated that having an autonomy-supportive physician was a very important and significant variable associated with high HIV treatment adherence, low depression and anxiety symptoms, higher perceptions of social support, and fewer experiences of stigma. These results are of great importance as they highlight the vital role physicians have on people's ability to successfully adhere to their prescribed HIV treatment regimens. Phase II findings demonstrated that autonomy is important but not necessary for successful HIV treatment adherence.

Health locus of control (HLOC). In Phase I, it was predicted that health locus of control (each subset of HLOC: Internal, Chance, Doctors, and Others) would be associated with intrinsic motivation (TSRQ), which in turn would be associated with HIV

treatment adherence. Each of the four hypotheses, testing the subscales of HLOC was not supported.

Internal HLOC. It was predicted that Internal HLOC would be associated with higher motivation to adhere to the HIV treatment, and as a result, with better adherence rates. This mediation was not supported and the results were in contrast to the findings reported by Affleck and colleagues (1987). One reason for the lack of supporting evidence for Internal HLOC may have been that the sample of PLWH in this study may not have felt that their health was entirely in their control. Instead, the participants may have placed more emphasis on other factors, perhaps more contextual circumstances. For example, in the literature, contextual factors found to impact adherence rates are lack of stable housing (Johnson, Catz, Remien, Rotheram-Borus, Morin, Charlebois, et al., 2003) or access to health care services (Johnson et al., 2006). Specifically for women, a large number of people that live in the same home and parenting stress are some gender specific factors found to influence HIV treatment adherence (Mellins, Kang, Leu, Havens, & Chesney, 2003). Unfortunately, Phase I was not designed to identify contextual factors associated with HIV treatment adherence, and it remained unclear what (if any) social circumstances may have been associated with adherence. This could be a direction for further research.

In Phase II, a few respondents supported the idea that contextual factors, outside of their control, can influence their HIV treatment adherence. For instance, two people indicated that the HIV medication that they took depended on their Ontario Disability Support Program (ODSP). Not all drugs are covered by the ODSP, and sometimes people need to switch medication in order to match this social service plan, or the

alternative would be to pay for the medication. One individual skipped a few weeks of medication because her ODSP coverage plan switched once she became a permanent resident (from a refugee status). The drugs that she was eligible to take, under the new ODSP plan, caused her many side effects, and she preferred to be without the treatment. Fortunately, this participant was able to resolve her situation; however, for many, especially with language barriers, challenging government policy may be outside of their control. Another individual indicated that his drug dependency and depression were associated with poor HIV treatment adherence. This finding is also consistent with the literature (Yun, Maravi, Kobayashi, Barton, & Davidson, 2005).

In summary, in Phase II, the interviewees generally indicated that they had some control over their health; however, they also found that there were other factors, outside of their control, that could make treatment adherence very difficult. Physicians treating HIV-positive patients need to be aware of the various social circumstances that can influence adherence. These physicians should also know and refer their patients to community resources where people can go for help.

In Phase I, bivariate correlations also revealed an unexpected pattern of association between Internal HLOC and the remaining sub-scales as part of the Health Locus of Control measure (Chance, Doctors, and Others). That is, people who perceived to have high Internal HLOC also perceived Chance, Doctors, and Other events to have some control over their health. This indicates that the PLWH in this sample had a more balanced view of the factors that influenced their health; that is, the participants viewed that things inside their control (Internal HLOC), outside (Chance HLOC), their physician (Doctors HLOC), and others factors (Others HLOC) combined to influence their health.

Phase II data indicated that the respondents mainly considered themselves and their doctor to be the two main factors in control of their health.

In sum, Internal HLOC was not significantly associated with HIV treatment adherence. In Phase II, however, participants identified government insurance plans and co-morbidities as factors outside of their control that may prevent successful HIV treatment adherence in this sample of PLWH.

Doctors HLOC. It was predicted that Doctors HLOC would be associated with high adherence rates, through intrinsic motivation as a mediator. Although this mediation was not supported, bivariate analysis revealed that *Doctors HLOC* was significantly associated with fewer symptoms of *depression* and higher *HIV treatment self-efficacy*.

Phase II indicated several examples of anecdotal evidence of the importance of Doctors HLOC. The sample of PLWH in Phase II indicated that their primary physician was an integral part of their HIV care, because they were the source of knowledge, support, and power to prescribe the HIV treatment. However, less is known in the literature about Doctors HLOC and HIV treatment adherence. Future research should further explore this construct and especially its relevance to patients' mental health.

Therefore, in the present study, Doctors HLOC proved to be an important variable, associated with lower depression scores, and higher HIV treatment self-efficacy, but this factor was not directly associated with HIV treatment adherence.

Chance HLOC. It was predicted that Chance HLOC (i.e., the idea that factors outside of a person's control can influence health) would be associated with lower motivation to adhere to the HIV treatment, and as a result, would predict worse adherence rates. This mediation was not supported. In the literature, less is known about Chance

HLOC and its influence on HIV treatment adherence. Furthermore, this is the first study to demonstrate a bivariate association between Chance HLOC and less knowledge about the HIV treatment (as assessed by the HIV treatment Knowledge Scale). Also bivariate analyses showed that participants high on Chance HLOC had lower HIV treatment self efficacy; in other words, these participants were less able to adhere to the HIV treatment when obstacles arose, as compared to individuals who believed that their health was influenced by factors other than chance.

In Phase II, the respondents did not comment on Chance HLOC as a factor that influenced their physical health. It should be noted, however, that participants were not asked about their perceptions of Chance HLOC, specifically, but rather a general questions was posed, asking what they perceived to be influencing their health. Their responses to this question related to either Internal HLOC or Doctors HLOC.

In summary, although Chance HLOC was associated with less HIV treatment knowledge and less HIV treatment self-efficacy, this variable was not directly associated with HIV treatment adherence.

Others HLOC. It was predicted that Others HLOC would be associated with lower motivation to adhere to the HIV treatment, and as a result, with worse adherence rates. This mediation was not supported. In Phase II of this study, Others HLOC did not emerge as a relevant variable associated with HIV treatment adherence. Less is known in the literature about this variable and HIV treatment adherence. Future studies should aim to better understand the influence Other HLOC may have on HIV treatment adherence rates.

Taken together, results from the data obtained from Phase I and II revealed interesting findings related to health locus of control and HIV treatment adherence. Specifically, in Phase I, with the exception of Doctors HLOC, the remaining subscales of health locus of control were not associated with HIV treatment adherence. The findings from Phase II, however, indicated a slightly more clear distinction of the factors that influence HIV treatment adherence; specifically, drug addictions and mental health diagnoses seemed to be barriers to successful adherence.

Relatedness

From a Self-Determination Theory perspective, relatedness is linked to a person's feelings of belongingness and connectedness. In the present study, therefore, relatedness was defined as perceived social support from friends and family, as well as perceived HIV-related stigma and discrimination from health care providers. In Phase I, the mediational hypotheses pertaining to relatedness were not supported.

Social support. It was predicted that social support would be associated with higher motivation to adhere to the HIV treatment, and as a result, would lead to better adherence rates. In Phase I, this mediation was not supported. It is not clear why in Phase I, social support was not a significant predictor of HIV treatment adherence, when the literature shows clear evidence for this association (Johnson et al., 2003; Roberts & Mann, 2000). Perhaps this sample of PLWH preferred to be more private about their diagnosis. Unfortunately, the present study did not assess for this possibility. Future studies might be strengthened by including an item concerning privacy about one's HIV status as part of the battery of questionnaires, or as part of an interview protocol.

The interviews from Phase II, however, offered more insight into the role of social support on people's experiences with their HIV treatment adherence. Two participants reported that their family members (romantic partners, or children) were a motivation for them to take their HIV treatment regularly. Specifically, one of the female participants indicated that her two young children and husband were her personal motivation to take the medication every day, despite the side effects that it caused. Qualitative research supports these findings (Remien, Hirky, Johnson, Weinhardt, Whittier, & Minh Le, 2003). Remien and colleagues (2003), found that among their sample of PLWH, children (especially for women), were a strong motivator for people to adhere to their HIV treatment regimens. In the present study (Phase II), one participant indicated that he sometimes forgot to take his medication on time, but that his fiancé was a very important motivator, and most importantly she also reminded him to stick to the prescribed treatment. The literature suggests that 63% of people indicate forgetfulness as a barrier to successful treatment adherence (Catz et al., 2000). Therefore, it was encouraging to see that family members can be a protective factor against non-adherence.

From the data on social support, we can conclude that based on the interviews from Phase II, social support was an important construct that helped PLWH to adhere to their prescribed treatment. The support of a loved one was a motivator to take the HIV treatment medication and stay healthy. In Phase I, however, social support did not emerge as a significant predictor of HIV-treatment adherence. More research is needed to understand these inconsistent findings.

HIV-related stigma in health care settings. It was predicted that perceived HIV-related stigma in health care settings would be associated with low motivation to

adhere to the HIV treatment, and as a result, this would be associated with poor adherence rates. In Phase I, this mediation was not supported, and this is in contrast to other published research (Rintamaki et al., 2006). Rintamaki and colleagues (2006) found that in a mixed gendered sample of PLWH, living in the United States, high perceptions of HIV-related social stigma were significantly associated with poor HIV treatment adherence. These researchers defined HIV-related social stigma using three items specifically related to concerns with the HIV treatment and public opinions. For example, one of the items was “I am embarrassed to get my medicines from a drug store”. A possible reason for why the present study failed to support the Rintamaki and colleagues (2006) study, may be as a result of how HIV treatment adherence was defined in the earlier study, as compared to the present study. Rintamaki et al. (2006) reported adherence as a dichotomous variable, which placed people into categories of 100% adherent or not adherent, if less than 100%. Although the researchers were not the first ones to measure HIV treatment adherence in this way (e.g., Gonzalez et al., 2004), this method was in sharp contrast to the continuous scale used for the analysis of HIV treatment adherence in Phase I of the present study; thus, the results may not be comparable. One problem with dichotomization of people into completely adherent (100% adherence rates), or not (<100%) categories, is that the results are less generalizable, as most PLWH are not actually 100% adherent. In addition, the present study may have been influenced by social desirability, and as a result, the respondents may not have been as accurate with their estimates of non-adherence. An extension of this study should use a more unbiased method of measuring adherence. This

will aid in better understanding of the role of HIV-related stigma on HIV treatment adherence rates.

Phase II further offered some insight into people's HIV stigma-related experiences and HIV treatment adherence. Close to half of the participants (54%) indicated that they had received less than adequate health care provision (from health care professionals, other than their family physician). Generally, the interviewees' dissatisfaction was related to the lack of ability to obtain service (e.g., obtaining a glass of water), perceived lack of communication with staff, and judgmental health care providers (e.g., judging the decision of an HIV-positive woman to become pregnant). When participants were asked, however, whether they thought that these negative experiences influenced their HIV treatment regimen, the majority of the respondents indicated that it did not affect them. Therefore, despite the negative attitudes that they had experienced, the participants indicated that they usually asked the questions that needed to be clarified.

In summary, Phase I did not find supporting evidence for relatedness (that is social support and HIV-related stigma in health care settings) and HIV treatment adherence. On the other hand, Phase II showed that social support from family members was a positive influence on treatment adherence. Furthermore, Phase II indicated that people generally experienced HIV stigma, but that these negative experiences did not affect their adherence rates. All together, there is support for relatedness as an important factor that influenced adherence rates; however, evidence for this only comes from the findings obtained from Phase II of the present study.

Competence

From the self-determination theory perspective, competence is defined as perceived ability to make a change. In the present study, competence was defined as the perceived ability to adhere to the HIV treatment regimen despite difficulties.

Competence was also defined as HIV treatment related knowledge. The mediational hypotheses pertaining to competence were not supported.

HIV treatment knowledge. In Phase I, the prediction was that low HIV treatment knowledge would be associated with lower intrinsic motivation and in turn poor HIV treatment adherence rates; this association was not supported. This hypothesis was based on past research that suggests that low HIV treatment knowledge is associated with low HIV treatment adherence rates (Balfour et al., 2007; Veinot et al., 2006; Weiss et al., 2003). A few reasons may have contributed to failing to support this hypothesis. One possibility is that the education level of the participants in the present study might be higher, as compared to the participants in other published studies. For example, in the present study, only 15.8% of the participants had less than high school education, as compared to 45.7% people who had less than a high school education in the study conducted by Weiss and colleagues (2003). Another reason for the inconsistent findings between HIV treatment knowledge and HIV treatment adherence may have been a result of the way HIV treatment knowledge was measured. Phase I used a validated measure for HIV treatment knowledge (*HIV Treatment Knowledge Scale*; Balfour et al., 2007). This is a recently developed and validated 21-item measure created by a Canadian team of researchers. Other studies (e.g., Kalichman et al., 2000) used a fourteen-item questionnaire to assess HIV treatment knowledge. These questions were created for the purpose of their study, and it is unclear if the questions were appropriately created; that is,

they may have been too easy or too difficult. It is recommended that future research assessing HIV treatment knowledge use validated measures to ensure that the questions assessing these constructs are of the appropriate level. In sum, the findings from Phase I did not find support for a relationship between low HIV treatment knowledge and poor HIV treatment adherence, and to date, the literature findings on this subject are very inconsistent.

The participants in Phase II of this study were aware of the importance of adhering to the HIV treatment. They indicated that missing medication builds HIV resistance. For the individuals concerned about their health, knowing this information seemed to be a motivator to adhere to their prescribed medication.

In general, the results of the present study added to the inconsistent findings reported in the literature on the relationship between HIV treatment knowledge and HIV treatment adherence. Statistical analysis, as part of Phase I, indicated that these two variables were not related. In Phase II, however, there was some anecdotal evidence that a person's motivation to adhere to the prescribed treatment may be influenced by their knowledge of the importance of medication adherence.

HIV treatment self-efficacy. In Phase I, it was predicted that HIV treatment self-efficacy would be associated with high intrinsic motivation, and in turn with better adherence rates. There is substantial evidence to suggest that treatment self-efficacy accounts for some of the variance in adherence rates (Cha et al., 2008; Johnson et al., 2007). In the present study, this prediction was not supported. Correlational analysis, however, revealed a strong relationship between *HIV treatment self-efficacy* (HIV-ASES) and *HIV treatment adherence*. It was also found that treatment self-efficacy mediated the

relationship between Chance HLOC and HIV treatment adherence, suggesting that people who have high self-efficacy can adhere better to their treatment, despite the fact that they attributed Chance to control their health. These findings have implications for improving HIV treatment adherence, such that fostering self-efficacy may lead to better medication adherence (Cha et al., 2008; Johnson et al., 2007). Some research suggests that self-efficacy can be increased with the support of family and friends (Van Servellen & Lombardi, 2005). Future research should focus on identifying other factors that may be associated with an increase in HIV treatment self-efficacy for PLWH.

In summary, competence was an important variable that influenced HIV-treatment adherence. Specifically, Phase I showed that HIV treatment self-efficacy had a significant impact on people's adherence rates, but HIV treatment knowledge did not. Future research should focus on creating intervention programs that aim to increase people's self-efficacy, as this in turn may improve adherence rates.

Additional findings

HIV-related coping. In Phase II, several people indicated that they preferred to forget about their HIV-status, and they would rather think of HIV 'as a flu that won't go away' or just avoid thinking about the disease all together. These reports of choosing to forget about the disease are consistent with other findings (Catz et al., 2000). Specifically, Catz and colleagues (2000) found that the item "Treatment reminds me that I am HIV-positive" as being the most frequently endorsed barrier to HIV treatment adherence. The current study was not designed to assess if 'not thinking about the virus' or 'denying the diagnosis' would influence the HIV treatment adherence rates. However, according to past research, not accepting the HIV diagnosis affects HIV treatment

adherence, and future research should focus on developing interventions that focus on helping PLWH to accept their diagnosis.

Co-morbidity. In Phase II, participants also indicated that there was lack of mental health care provision for people diagnosed with HIV and a mental health condition (e.g., depression or drug dependency). For example, it was found that people who had mental health conditions, in addition to their HIV diagnosis, did not obtain the necessary services that they required; these people did not have access to a mental health professional, or if they did, it was only in emergencies. Therefore, based on the findings from Phase II, more mental health services are needed for PLWH. In order to improve their quality of life and eliminate some of the barriers to successful HIV treatment adherence, interventions aimed to address mental health issues are needed.

Strengths and Limitations

Strengths

Although none of the hypothesized mediations were supported, this study was able to provide a number of important insights about the psychosocial and demographic factors that influence HIV treatment adherence. Specifically, Phase I (correlational analysis) found that younger age, lack of autonomy-supportive physicians, headache as side effects, and low HIV treatment self-efficacy were associated with poor HIV treatment adherence. The results of this study add to the literature by providing a more comprehensive understanding of people's experiences taking and adhering to their prescribed HIV treatment regimens.

Secondly, this is one of the first studies to examine HIV-related stigma in Canadian health care settings and its impact on HIV treatment adherence. Fortunately,

through Phase I, it was found that only some people experienced HIV-related stigma. Conversely, the findings as part of Phase II indicated that more than half of the people had numerous negative experiences with health care providers (in hospital settings only), but these experiences were not related to adherence rates. Although HIV-related stigma in health care settings was not related to adherence rates, the importance of knowing more about the quality of health care provision for PLWH was evident from the present study.

Another strength of this study was that, except for the measure assessing HIV-stigma in health care settings, all other measures used in Phase I were validated and have previously been used with HIV positive populations. The HIV-related stigma scale was created for the purpose of the present study because, to date, a measure assessing this variable has not been created.

In addition, the present study employed a mixed methods research design. Thus, the findings were triangulated using self-report questionnaire data as well as anecdotal accounts obtained through semi-structured interview data.

Limitations

Despite the important findings and strengths of the present study, this study also had a number of limitations, which are outlined below. The use of self-report adherence data has been questioned because of recall and social desirability bias (Johnson, Chesney, Goldstein, et al., 2006; Johnson, Dilworth, Taylor, & Neilands, 2011). Currently, there are no acceptable criteria for measuring HIV treatment adherence (Johnson et al., 2006). However, future research replicating this study should utilize several techniques when measuring adherence (e.g., Johnson et al., 2006). For example, in addition to patient self-

report, researchers can use electronic pill bottle monitoring (e.g., Medication Event Monitoring System; see Paterson, Swindells, Mohr, Brester, Vergis, & Squier, 2000), blood testing (i.e., plasma drug testing), or monitor pharmacy refill patterns.

In addition, no hypothesized mediations were supported. It is likely that the study in Phase I required a larger sample size to detect any significant relationships. The small sample size also precluded the testing of the entire model. That is, a larger sample would have allowed for the use of a more powerful statistical analysis, which would include all the variables simultaneously based on the theoretical grounds of Self-Determination Theory. As a result of the small sample size, only independent pieces of the theory were examined, rather than the whole model.

Some of the measures, including the measure for HIV treatment adherence (the dependent variable), had low alpha reliabilities, which decreased the power to detect any significant differences. It is also possible that not enough information was obtained to account for other possible relationships. For instance, when assessing autonomy-supportive physicians, the dynamic relationship between the physician and the patient could have been influenced by additional variables, such as the physician's gender or ethnicity (Hall, Roter, & Katz, 1988; Street, 2002). These additional variables were not assessed in the present study. Future research should narrow its focus and obtain a more comprehensive and in-depth understanding of the factors that may influence autonomy-supportive physician-patient communication, and use measures that yield higher alpha reliabilities. Lastly, it is also reasonable to assume that the components of Self-Determination Theory that were tested may not apply to the unique subpopulation of PLWH who participated in this study - primarily white gay men with access to AIDS

Service Organizations (ASOs). Future studies using more diverse samples of PLWH will be needed to assess the applicability of SDT to PLWH.

Moreover, although the educational level of respondents in Phase I was high, the questionnaire was limited to participants who could only read and write in English. Therefore, the potential experiences of PLWH with low literacy in English were not obtained. Phase II, however, was not limited to people with English literacy, but it did require people to be able to speak and understand English. Furthermore, all the participants in the present study were only recruited from ASOs, which means that PLWH not in contact with ASOs did not have the chance to participate in this study. The sample of PLWH who were in contact with ASOs were likely more motivated to obtain help, more involved with their community, and it was more likely that they spoke English, as compared to PLWH who did not seek the services of such community organizations. Therefore, the findings in the present study are not intended to be generalized to all PLWH. Also, the subsamples of participants who took part in Phase I and II likely differed in some characteristics, because a majority of Phase II participants were without stable homes and required the housing services of an organization, whereas the majority of Phase I participants were not at risk for being homeless. Therefore, the results from Phase I and II may not have been entirely comparable.

The findings presented in this study were based on cross-sectional data. For this reason, conclusions about causality among the relationships tested could not be reached. The present study relied on a large number of Pearson-product moment correlations; therefore, one has to be cautious of Type I error. It may be necessary to employ longitudinal research to posit any causal relationships among the variables tested in the

present study and HIV treatment adherence. Furthermore, in Phase II, the respondents who took part in the face-to-face interviews may have been influenced by social desirability bias; that is, the tendency for the respondent to be influenced by the researcher (Nederhof, 1985). This may explain the fact that only 18% (2 out of 11) said that they sometimes forgot to take their medication; this was in sharp contrast to the adherence rates found through the self-report questionnaires (42% non-adherent). One way to account for social desirability bias, and not depend on self-report questionnaires, is the use of computer programs like the ACASI (Audio Computer Assisted Self Interview). ACASI has been successfully used in research that requires participants to respond to sensitive questions; for example, research on sexual risk taking frequently employs the use of ACASI (e.g., Ghanem, Hutton, Zenilman, Zimba, & Erbelding, 2004).

Conclusions and Future Directions

Despite these limitations, the present study shed additional light on the factors associated with HIV treatment adherence. Some very important relationships were noted, and one of particular importance was the role of the health care providers on people's HIV treatment adherence rates. Future efforts should be made to create interventions aimed to promote a patient-practitioner alliance where the physician allows the patient to have some control (autonomy) over their treatment management, as this may result in better adherence rates and better physical health for PLWH. Moreover, physicians should be aware that some of the HIV treatment-related side effects are significant barriers to successful adherence. Physicians treating PLWH should spend the time to discuss with their patients the potential treatment-related side effects and techniques for

managing them, as this could improve the quality of life, treatment options, and increase adherence rates in their patients.

Furthermore, the participants in Phase II reported anecdotal evidence of stigma and discrimination in health care settings against PLWH. These findings could be used to inform the design of programs and interventions to reduce HIV-related stigma in health care settings as their primary goal, and elements of these efforts should be to inform patients of the importance of HIV treatment adherence. Improving the quality of health care provision in hospitals may improve the health of PLWH, and most importantly, the patients will receive the sensitive health care that they need and deserve.

Lastly, a patient-specific recommendation would be to increase people's HIV treatment self-efficacy. This could be done by creating safe social support networks for PLWH to be able to share their concerns, experiences, and find reassurance. Social support and having the encouragement of a loved one can be powerful motivators for PLWH to adhere to their treatment and increase their HIV treatment self-efficacy. Increasing patients' perceived ability to adhere to the HIV treatment despite obstacles should be an important aspect of any interventions aimed to improve medical adherence.

Many PLWH successfully adhere to their prescribed HIV treatments; however, for the people that require some assistance, sensitive HIV care, social support, and available health services to assist clients to adhere to their HIV treatments could all improve the health of people living with HIV in Canada.

References

- Affleck, G., Tennen, H., Pfeiffer, C., & Fifield, J. (1987). Appraisals of control and predictability in adapting to a chronic disease. *Journal of Personality and Social Psychology*, 53, 273-279. doi:10.1037/0022-3514.53.2.273
- Ammassari, A., Trotta, M. P., Murri, R., Castelli, F., Narciso, P., Noto, P., ... for the AdICoNA Study Group. (2002). Correlates and predictors of adherence to highly active antiretroviral therapy: Overview of published literature. *Journal of Acquired Immune Deficiency Syndromes*, 31, 123-127.
- Amico, K. R., Konkle-Parker, D. J., Cornman, D. H., Barta, W. D., Ferrer, R., Norton, W. E. (2007). Reasons for ART non-adherence in the Deep South: Adherence needs of a sample of HIV positive patients in Mississippi. *AIDS Care*, 19, 1210-1218. doi:10.1080/09540120701426516
- Baron, R. M., & Kenny, D. A. (1986). The moderator–mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, 51, 1173-1182. doi: 10.1037/0022-3514.51.6.1173
- Bangsberg, D. R., Hecht, F. M., Charlebois, E. D., Zolopa, A. R., Holodniy, M., Sheiner, L., ... Moss, A. (2000). Adherence to protease inhibitors, HIV-1 viral load, and development of drug resistance in an indigent population. *AIDS*, 14(4), 357-366.
- Barclay, T. R., Hinkin, C. H., Castellon, S. A., Mason, K. I., Reinhard, M. J., Marion, S. D., ... Durvasula, R. S. (2007). Age-associated predictors of medication adherence in HIV-positive adults: Health beliefs, self-efficacy, and neurocognitive status. *Health Psychology*, 26, 40-49. doi: 10.1037/0278-6133.26.1.40
- Balfour, L., Kowal, J., Tasca, G. A., Cooper, C. L., Angel, J. B., MacPherson, P. A., ... Cameron, D. W. (2007). Development and psychometric validation of the HIV Treatment Knowledge Scale. *AIDS Care*, 19, 1141-1148. doi:0.1080/09540120701352241
- Bjelland, I., Dahl, A. A., Haug T. T., & Neckelmann, D. (2002). The validity of the hospital anxiety and depression scale: An updated literature review. *Journal of Psychosomatic Research*, 52, 69-77. doi:10.1016/S0022-3999(01)00296-3
- Bogart, L. M., Catz, S. L., Kelly, J. A., Gray-Bernhardt, M. L., Hartmann, B. R., Otto-Salaj, L. L., ... Bloom, F. R. (2000). Psychosocial issues in the era of new AIDS treatments from the perspective of persons living with HIV. *Journal of Health Psychology*, 5, 500-516. doi: 10.1177/135910530000500408
- Bowman, F. M., Goldberg, D. P., Millar, T., Gask, L., & McGrath, G. (1992). Improving the skills of established general practitioners: The long-term benefits of group teaching. *Medical Education*, 26.

- Catz, S. L., Kelly, J. A., Bogart, L. M., Benotsch, E. G., & McAuliffe, T. M. (2000). Patterns, correlates, and barriers to medication adherence among persons prescribed new treatments for HIV disease. *Health Psychology, 19*, 124-133. doi:10.1037/0278-133.19.2.124
- Cha, E., Erlen, J. A., Kim, K. H., Sereika, S. M., & Caruthers, D. (2008). Mediating roles of medication-taking self-efficacy and depressive symptoms on self-reported medication adherence in persons with HIV: A questionnaire survey. *International Journal of Nursing Studies, 45*, 1175-1184. doi:10.1016/j.ijnurstu.2007.08.003
- Charbonneau, D., Barling, J., & Kelloway, E. K. (2001). Transformational leadership and sports performance the mediating role of intrinsic motivation. *Journal of Applied Social Psychology, 31*, 1521-1534. doi: 10.1111/j.1559-1816.2001.tb02686.x
- Chesney, M. A., Morin, M., & Sherr, L. (2000a). Adherence to HIV combination therapy. *Social Science & Medicine, 50*, 1599-1605. doi:10.1016/S0277-9536(99)00468-2
- Chesney, M. A., Ickovics, J. R., Chambers, D. B., Gifford, A. L., Neidig, J., Zwickl, B., ... Patient care committee and adherence working group of the outcomes committee of the Adult AIDS Clinical Trials Group (AACTG). (2000b). Self-reported adherence to antiretroviral medications among participants in HIV clinical trials: the AACTG adherence instruments. *AIDS Care, 12*, 255-266. doi:10.1080/09540120050042891
- Cohen, S., Sherrod, D. R., & Clark, M. S. (1986). Social skills and the stress-protective role of social support. *Journal of Personality and Social Psychology, 50*, 963-973. doi:10.1037/0022-3514.50.5.963
- Cobb, M., & DeChabert, J. T. (2002). HIV/AIDS and care provider attritions: Who's to blame? *AIDS Care, 14*(4), 545-548.
- Cook, J. A., Grey, D. D., Burke-Miller, J., Cohen, M. H., Anastos, K., Gandhi, M., ... Young, M. (2006). Effects of treated and untreated depressive symptoms on highly active antiretroviral therapy use in a US multi-site cohort of HIV-positive women. *AIDS Care, 18*(2), 93-100.
- Cook, J. A., Grey, D., Burke, J., Cohen, M. H., Gurtman, A. C., Richardson, J. L., ... Hessol, N. A. (2004). Depressive symptoms and AIDS related mortality among a multisite cohort of HIV-positive women. *American Journal of Public Health, 94*(7), 1133-1140. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1448411/pdf/0941133.pdf>
- Corsonello, A., Pedone, C., Lattanzio, F., Lucchetti, M., Garasto, S., Carbone, C., ... Incalzi, A. (2009). Regimen complexity and medication nonadherence in elderly patients. *Therapeutics and Clinical Risk Management, 5*(1), 209-216.

Cooper, E. R., Charurat, M., Mofenson, L., Hanson, C., Pitt, J., Diaz, C., ... for the Women and Infants' Transmission Study Group. (2002). Combination Antiretroviral Strategies for the

Treatment of Pregnant HIV-1–Infected Women and Prevention of Perinatal HIV-1 Transmission. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 29, 484–494.

Davey, M.P., Foster, J., Milton, K., & Duncan, T.M. (2009). Collaborative approaches to increasing family support for HIV positive youth. *Families, Systems, & Health*, 27, 39-52. doi:10.1037/a0014910

Davies, S.L., Horton, T.V., Williams, A.G., Martin, M.Y., & Stewart, K.E. (2009). MOMS: Formative evaluation and subsequent intervention for mothers living with HIV. *AIDS Care*, 21, 552-560. doi:10.1080/09540120802301832

Davison, K.P., Pennebaker, J.W., & Dickerson, S.S. (2000). Who talks? The social psychology of illness support groups. *American Psychologist*, 55(2), 205-217.

Deci, E. L., Ryan, R. M. (1985). *Intrinsic motivation and self-determination in human behavior*. New York, NY: Plenum Press.

Deci, E. L., & Ryan, R. M. (Eds.). (2002). *Handbook of self-determination research*. Rochester, NY: The university of Rochester Press.

Deber, R. B., Kraetschmer, N., Urowitz, S., & Sharpe, N. (2007). Do people want to be autonomous patients? Preferred roles in treatment decision-making in several patient populations. *Health Expectations*, 10, 248–258. doi:10.1111/j.1369-7625.2007.00441.x

Dilorio, C., McCarty, F., DePadilla, L., Resnicow, K., Holstad, M.M., Yeager, K., ... Lundberg, B. (2007). Adherence to antiretroviral medication regimens: A test of a psychosocial model. *AIDS Behavior*, 13, 10–22. doi:10.1007/s10461-007-9318-4

Dodds, C., Coleman, R., Amaratunga, C., & Wilson, J. (2001). The cost of HIV/AIDS in Canda. Availble at: <http://gpiatlantic.org/pdf/health/costofaids.pdf>

Dunbar-Jacob, J., Burke, L.E., & Puczynski, S. (1995). Clinical assessment and management of adherence to medical regimens. In P.M. Nicassio & T.W. Smith (Eds.), *Managing chronic illnesses: A biopsychosocial perspective* (pp.313-349). Washington, DC: American Psychological Association.

Durham, J. D., & Lashley, F. R. (Ed.). (2010). *The person with HIV/AIDS: Nursing perspectives* (4 ed.). New York, NY: Springer Publisher.

Elford, J., Ibrahim, F., Bukutu, C., & Anderson J. (2008). HIV-Related Discrimination Reported by People Living with HIV in London, UK. *AIDS and Behaviour*, 12, 255–264. doi:10.1007/s10461-007-9344-2

- Farmer, P., Leandre, F., Mukherjee, J., Gupta, R., Tarter, L., & Kim, J.Y. (2001). Community-based treatment of advanced HIV disease: Introduction DOT-HAART (directly observed therapy with highly active antiretroviral therapy). *Bulletin World Health Organization*, 79(12), 1145-1151.
- Fothergill-Bourbonnais, F., Laschinger, S., RN, Fillion, D., Denommé, N., Conway-Vendette, J., O'Reilly, L., ... Thibert, J. (2002). The experience of taking multiple drug therapies for persons with HIV Infection: The Canadian perspective. *Journal of the Association of Nurses in AIDS Care*, 13, 32-42. doi:10.1016/S1055-3290(06)60369-5
- Gao, X., Nau, D.P., Rosenbluth, S.A., Scott, V., & Woodward, C. (2000). The relationship of disease severity, health beliefs and medication adherence among HIV patients. *AIDS Care*, 12(4), 387-398.
- Ghanem, K. G., Hutton, H. E., Zenilman, J. M., Zimba, R., & Erbedding, E. J. (2005). Audio computer assisted self interview and face to face interview modes in assessing response bias among STD clinic patients. *Sex Transm Infect*, 81, 421-425. doi:10.1136/sti.2004.013193
- Gonzalez, J. S., Penedo, F. J., Antoni, M. H., Duran, R. E., Fernandez, M. I., McPherson-Baker, S., ... Schneiderman, N. (2004). Social Support, Positive States of Mind, and HIV Treatment Adherence in Men and Women Living With HIV/AIDS. *Healthy Psychology*, 23, 413-418. doi:10.1037/0278-6133.23.4.413
- Gordillo, V., Amo, J., Soriano, V., & González-Lahoz, J. (1999). Sociodemographic and psychological variables influencing adherence to antiretroviral therapy. *AIDS*, 13:1763-1769.
- Hall, J. A., Roter, D. L., & Katz, N. R. (1988). Meta-analysis of correlates of provider behavior in medical encounters. *Medical Care*, 26(7), 657-670.
- Halkitis, P.N., Shrem, M.T., & Zade, D.D. (2005). The physical, emotional and interpersonal impact of HAART: Exploring the realities of HIV seropositive individuals on combination therapy. *Journal of Health Psychology*, 10, 345-358.
- Herek, G. M., & Glunt, E. K. (1988). An epidemic of stigma: Public reactions to AIDS. *American Psychologist*, 43, 886-891. doi: 10.1037/0003-066X.43.11.886
- Ironson, G., O'Cleirigh, C., Fletcher, M.N., Laurenceau, J. P., Balbin, E., Klimas, N. ... Solomon, G. (2005). Psychosocial factors predict CD4 and viral load change in men and women with human immunodeficiency virus and the era of highly active antiretroviral treatment. *Psychosomatic Medicine*, 67, 1013-1021. doi:10.1097/01.psy.0000188569.58998.c8

Jamshidian, M., & Bentler, P. M. (1999). ML Estimation of Mean and Covariance Structures with Missing Data Using Complete Data Routines. *Journal of Educational and Behavioral Statistics*, 24, 21-41. doi:10.3102/10769986024001021

Johnson, M. O., Catz, S. L., Remien, R. H., Rotheram-Borus, M. J., Morin, S. F., Charlebois, E., ... the NIMH Healthy Living Project Team. (2003). *AIDS Patient Care and STDs*, 17, 645-656. doi:10.1089/108729103771928708.

Johnson, M. O., Neilands, T. B., Dilworth, S. E., Morin, S. F., Remien, R. H., & Chesney, M. A. (2007). The role of self-efficacy in HIV treatment adherence: Validation of the HIV treatment adherence self-efficacy scale (HIV-ASES). *Journal of Behavioral Medicine*, 30, 359-370. doi:10.1007/s10461-007-9229-4

Johnson, M. O., Chesney, M. A., Goldstein, R. B., Remien, R. H., Catz, S., Gore-Felton, C., ... The NIMH Healthy Living Project Team. (2006). Positive provider interactions, adherence self-efficacy, and adherence to antiretroviral medications among HIV-infected adults: A mediation model. *AIDS Patient Care and STDs*, 20, 258-268. doi:10.1089/apc.2006.20.258.

Johnson, M. O., Catz, S. L., Remien, R. H., Rotheram-Borus, M. J., Morin, S. F., Charlebois, E., ... The NIMH Healthy Living Project Team. (2003). Theory-guided, empirically supported avenues for interventions on HIV medication nonadherence: Findings from the health living project. *AIDS Patient Care and STD's*, 17, 645-656. doi:10.1089/108729103771928708.

Kalichman, S. C., & Rompa, D. (2000). Functional health literacy is associated with health status and health-related knowledge in people living with HIV-AIDS. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 25(4), 337-344.

Kalichman, S. C., Cherry, J., & Cain, D. (2005). Nurse-delivered antiretroviral treatment adherence intervention for people with low literacy skills and living with HIV/AIDS. *Journal of the Association of Nurses in AIDS Care*, 16, 3-15. doi:10.1016/j.jana.2005.07.001

Kalichman, S. C., DiMarco, M. Austin, J., Luke, W., & DiFonzo, K. (2003). Stress, social support, and HIV-status disclosure to family and friends among HIV-positive men and women. *Journal of Behavioral Medicine*, 26, 315-332. doi:10.1023/A:1024252926930

Kitahata, M. M., Gange, S. J., Abraham, A. G., Merriman, B., Saag, M. S., Justice, A. C., ... Moore, R. D. (2009). Effect of Early versus Deferred Antiretroviral Therapy for HIV on Survival. *New England Journal of Medicine*, 360, 1815-1826. doi:10.1056/NEJMoa0807252

- Kennedy S, Goggin K, & Nollen N. (2004). Adherence to HIV medications: Utility of the theory of self-determination. *Cognitive Therapy and Research*, 28, 611–628. doi:10.1023/B:COTR.0000045568.95219.e2
- Landsbergis, P. A. (1988). Occupational stress among health care workers: A test of the job demands-control model. *Journal of Organizational Behaviour*, 9, 217-239. doi:10.1002/job.4030090303
- Lee, K., Solts, B., & Burns, J. (2002). Investigating the psychosocial impact of anti-HIV combination therapies. *AIDS Care*, 14, 851–857. doi:10.1080/0954012021000031912
- Leserman, J., Jackson, E. D., Petitto, J. M., Golden, R. N., Silva, S. G., Perkins, D. O., ... Evans, D. L. (1999). Progression to AIDS: The effects of stress, depressive symptoms, and social support. *Psychosomatic Medicine*, 61(3), 397-406.
- Levesque, C. S., Williams, G. C., Elliot, D., Pickering, M. A., Bodenhamer, B., & Finley, P. J. (2007). Validating the theoretical structure of the Treatment Self-Regulation Questionnaire (TSRQ) across three different health behaviors. *Health Education Research*, 22, 691-702. doi:10.1093/her/cyl148
- Levenson, H. (1973). Multidimensional locus of control in psychiatric patients. *Journal of Consulting and Clinical Psychology*, 41, 397-404. doi: 10.1037/h0035357
- Li, L., Wu, Z., Wu, S., Zhaoc, Y., Jia, M., & Yan, Z. (2007). HIV-related stigma in health care settings: A survey of service providers in China. *AIDS Patient Care STDS*, 21, 753–762. doi:10.1089/apc.2006.0219
- Lynam, I., Catley, D., Goggin, K., Rabinowitz, J. L., Gerkovich, M. M., Williams, K., ... MOTIV8. (2009). Autonomous regulation and locus of control as predictors of antiretroviral medication adherence. *Journal of Health Psychology*, 14, 578-586. doi:10.1177/1359105309103577
- Lyketsos, C. G., Hoover, D. R., Guccione, M., Dew, M. A., Wesch, J. E., Bing, E. G., & Treisman, G. J. (1996). Changes in depressive symptoms as AIDS develops. The multicenter AIDS cohort study. *American Journal of Psychiatry*, 153(11), 1430-1437.
- Mannheimer, S. B., Mukherjee, R., Hirschhorn, L. R., Dougherty, J., Celano, S. A., Ciccarone, D., ... Finkelstein, R. (2006). The CASE adherence index: A novel method for measuring Adherence to antiretroviral therapy. *AIDS Care*, 18, 853-861. doi:10.1080/09540120500465160
- Meichenbaum, D., & Turk, D. C. (1987). *Facilitating treatment adherence: A practitioner's guidebook*. New York: Plenum Press.
- Mehta, S., Moore, R. D., & Graham, N. (1997). Potential factors affecting adherence with HIV therapy. *JAIDS*, 11(14), 1665-1670.

Mele, A. R. (1995). *Autonomous agents: From self-control to autonomy*. New York: Oxford University Press.

Mellins, C. A., Kang, E., Leu, C. S., Havens, J. F., & Chesney, M. (2003). Longitudinal study of mental health and psychosocial predictors of medical treatment adherence in mothers living with HIV disease. *AIDS Patient Care and STDs*, 17, 407-416. doi:10.1089/108729103322277420.

Mellors, J. W., Rinaldo, C. R., Gupta, R., White, R. M., Todd, J. A., & Kingsley, L. A. (1996). Prognosis in HIV-1 Infection predicted by the quantity of virus in plasma. *Science*, 272, 1167-1170. doi:10.1126/science.272.5265.1167

Mizuno, Y., Purcell, D. W., Dawson-Rose, C., Parsons, J. T., & The Suids Team. (2003). Correlates of depressive symptoms among HIV-positive injection drug users: The role of social support. *AIDS Care*, 15(5), 689-698.

Molassiotis, A., Nahas-Lopez, V., Chung, W. Y., Lam, S. W, Li, C. K., & Lau, T. F. (2002). Factors associated with adherence to antiretroviral medication in HIV-infected patients. *International Journal of STD & AIDS*, 13, 301-310. doi:10.1258/0956462021925117

Molleman, E., Krabbenda, P. J., Annyas, A. A., Koops, H. S., Sleijfer, D. T., & Vermey, A. (1984). The significance of the doctor-patient relationship in coping with cancer. *Social Science and Medicine*, 18, 475-480. doi:10.1016/0277-9536(84)90003-0

Molinary, V., & Khanna, P. (1981). Locus of control and its relationship to anxiety and depression. *Journal of Personality Assessment*, 45, 314-319. doi:10.1207/s15327752jpa4503_14

Moral, R. R., Alamo, M. M., Jurado, M. A., & Torres, L. P. (2001). Effectiveness of a learner-centred training programme for primary care physicians in using a patient-centred consultation style. *Family Practice*, 18, 60-63. doi: 10.1093/fampra/18.1.60

Miguez-Burbano, M. J., Espinoza, L., & Lewis, J. E. (2008). HIV Treatment Adherence and sexual functioning. *AIDS and Behavior*, 12, 78-85. doi:10.1007/s10461-006-9197-0

Miller, W. R., Benefield, R. G., & Tonigan, J. S. (1993). Enhancing motivation for change in problem drinking: A controlled comparison of two therapist styles. *Journal of Consulting and Clinical Psychology*, 61, 455-461. doi: 10.1037/0022-006X.61.3.455

Nieuwkerk, P. T. & Oort, F. J. (2005). Self-reported adherence to antiretroviral therapy for HIV-1 Infection and virologic treatment response: A meta-analysis. *Journal of Acquired Immune Deficiency Syndromes*, 38(4), 445-448.

Nundy, S. (2010). *Stay healthy at every age: What your doctor wants you to know*. Baltimore, Maryland: The Johns Hopkins University Press

Ong, L. M., De Haes, J. C., Hoos, A. M., & Lammes, F. B. (1995). Doctor-patient communication: A review of the literature. *Social Science Medicine*, 40, 903-918. doi:10.1016/0277-9536(94)00155-M

Parsons, J. T., Rosof, E., & Mustanski, B. (2008). The temporal relationship between alcohol consumption and HIV-medication adherence: A multilevel model of direct and moderating effects. *Health Psychology*, 27, 628-637. doi:10.1037/a0012664

Paterson, D. L., Swindells, S., Mohr, J., Brester, M., Vergis, E. N., Squier, C., ... Singh, N. (2000). Adherence to protease inhibitor therapy and outcomes in patients with HIV infection. *Ann Intern Med*, 133, 21-30.

Pelletier, L. G., Fortier, M. S., Vallerand, R. J. & Bri`ere, N. M. (2001). Associations among perceived autonomy support, forms of self-regulation, and-persistence: A prospective study. *Motivation and Emotion*, 25, 279-306. doi: 0146-7239/01/1200-0279/0

Preacher, K. J., & Hayes, A. F. (2004). SPSS and SAS procedures for estimating indirect effects in simple mediation models. *Behavior Research Methods, Instruments, & Computers*, 36(4), 717-731.

Public Health Agency of Canada. (2009). *Summary: Estimates of HIV Prevalence and incidence in Canada, 2008*. Surveillance and risk assessment division, Centre for Communicable Diseases and Infection Control.

Reif, S., Golin, C. E., & Smith, S. R. (2005). Barriers to accessing HIV/AIDS care in North Carolina: Rural and urban differences. *AIDS Care*, 17, 558-565. doi:10.1080/09540120412331319750

Reilly, T., & Woo, G. (2004). Social support and maintenance of safer sex practices among people living with HIV/AIDS. *Health and Social Work*, 29(2), 97-105.

Remien, R. H., Hirky, E. A., Johnson, M. O., Weinhardt, L. S., Whittier, D., & Le, G. M. (2003). Adherence to Medication Treatment: A Qualitative Study of Facilitators and Barriers Among a Diverse Sample of HIV+ Men and Women in Four U.S. Cities. *AIDS and Behavior*, 7, 61-72. doi:1090-7165/03/0300-0061/0

Rintamaki, L. S., Davis, T. C., Skripkauskas, S., Bennett, C. L., & Wolf, M. S. (2006). Social stigma concerns and HIV medication adherence. *AIDS Patient CARE and STDs*, 20(5), 359-368.

Roberts, K. J. & Mann, T. (2000). Barriers to antiretroviral medication adherence in HIV-infected women. *AIDS Care*, 12, 377-386. doi:10.1177/0044118X05278269

Rothbaum, F., Weisz, J. R., & Snyder, S. S. (1982). Changing the world and changing the self: A two-process model of perceived control. *Journal of Personality and Social Psychology*, 42, 5-37. doi:10.1037/0022-3514.42.1.5

Ryan, R. M., La Guardia, J. G., Solky-Butzel, J. I., Chirkov, V., & Kim, Y. (2001). On the interpersonal regulation of emotions: Emotional reliance across gender, relationships, and cultures. *Personal Relationships*, 12, 145-163. doi:10.1111/j.1350-4126.2005.00106.x

Savard, J., Laberge, B., Gauthier, J. G., Ivers, H., & Bergeron, M. G. (1998). Evaluating anxiety and depression in HIV-Infected patients. *Journal of Personality Assessment*, 71, 349-367. doi:10.1207/s15327752jpa7103_5

Serovich, J. M., Kimberly, J. A., Mosack, K. E., & Lewis, T. L. (2001). The role of family and friend social support in reducing emotional distress among HIV-positive women. *AIDS Care*, 13, 335-341. doi:10.1080/09540120120043982

Simoni, J. M., Frick, P. A., & Huang, B. (2006). A longitudinal evaluation of a social support model of medication adherence among HIV-positive men and women on antiretroviral therapy. *Health Psychology*, 25, 74-81. doi:10.1037/0278-6133.25.1.74

Shilts, R. (1987). *And the band played on. Politics, People, and the AIDS Epidemic*. NY.

Shrout, P. E., & Bolger, N. (2002). Mediation in experimental and nonexperimental studies: New procedures and recommendations. *Psychological Methods*, 7, 422-445. doi:10.1037//1082-989X.7.4.422

Schneider, J., Kaplan, S. H., Greenfield, S., Li, W., & Wilson, I. B. (2004). Better physician-patient relationships are associated with higher reported adherence to antiretroviral therapy in patients with HIV infection. *Journal of General Internal Medicine*, 19, 1096-1103. doi:10.1111/j.1525-1497.2004.30418.x

Street, R. L. (2002). Gender differences in health care provider-patient communication: are they due to style, stereotypes, or accommodation? *Patient Education and Counseling*, 48(3), 201-206.

Strecher, V. J., Devellis, B. M., Becker, M. H., Rosenstock, I. M. (1986). The role of self-efficacy in achieving health behavior change. *Health Education Quarterly*, 13, 73-91.

Tucker, J. S., Brunam, M. A., Sherbourne, C. D., Kung, F. Y., & Gifford, A. L. (2003). Substance use and mental health correlates of nonadherence to antiretroviral medications in a sample of patients with human immunodeficiency virus infection. *American Journal of Medicine*, 114(7), 573-580. doi:10.1016/S0002-9343(03)00093-7

Thorndike, A. N., Rigotti, N. A., Stafford, R. S., & Singer, D. E. (1998). National patterns in the treatment of smokers by physicians. *JAMA*, 279, 604-608. doi: 10.1001/jama.279.8.604

Thompson, C. E., & Wankel, L. M. (1980). The effects of perceived activity choice upon frequency of exercise behavior. *Journal of Applied Social Psychology*, 10, 436-443. doi:10.1111/j.1559-1816.1980.tb00722.x

USAID. (2009). *HIV/AIDS frequently asked questions*. Retrieved from http://www.usaid.gov/our_work/global_health/aids/News/aidsfaq.html

UNAIDS, World Health Organization, Joint United Nations Programme on HIV/AIDS and World Health Organization. (2009). *AIDS Epidemic Update: December 2009*. Retrieved from http://data.unaids.org/pub/Report/2009/JC1700_Epi_Update_2009_en.pdf.

Van Servellen, G., & Lombardi, E. (2005). Supportive relationships and medication adherence in HIV-infected, low-income Latinos. *Western Journal of Nursing Research*, 27, 1023-1039. doi:10.1177/0193945905279446

Veinot, T. C., Flicker, S. E., Skinner, H. A., McClelland, A., Saulnier, P., Stanley, S. E., ...Goldberg, E. (2006). "Supposed to make you better but it doesn't really": HIV-positive youths' perceptions of HIV treatment. *Journal of Adolescent Health*, 38, 261-267. doi:10.1016/j.jadohealth.2005.03.008

Wagner, A. C, Hart, T. A., Mohammed, S., Ivanova, E., Wong, J., & Loutfy, M. (2010). Correlates of HIV stigma in HIV Positive (HIV+) Women. *Archives of Women's Mental Health*, 13, 207-214. doi:10.1007/s00737-010-0158-2

Wallston, K. A., Stein, M. J., & Smith, C. A. (1994). Form C of the MHLC scales: A condition-specific measure of locus of control. *Journal of Personality Assessment*, 63(3), 534-553.

Wallston, K. A., Wallston, B. S., & DeVellis, R. (1978). Development of the multidimensional Health Locus of Control (MHLC) Scales. *Health Education & Behavior*, 6, 160-167. doi:10.1177/109019817800600107

Ware, N. C., Wyatt, M. A., & Tugenberg, T. (2006). Social relationships, stigma and adherence to antiretroviral therapy for HIV/AIDS. *AIDS Care*, 18(8), 904-910.

Weiss, L., French, T., Finkelstein, R., Waters, M., Mukherjee, R., & Agins, B. (2003). HIV-related knowledge and adherence to HAART. *AIDS Care*, 15(5); 673-79. doi:10.1080/09540120310001595159

Weeks, B. S., & Alcamo, I. E. (2006). *AIDS: The Biological Basis*. Boston: Jones and Bartlett.

Wilson, P. M., Blanchard, C. M., Nehl, E., & Baker, F. (2006). Predicting physical activity and outcome expectations in cancer survivors: an application of self-determination theory. *Psycho-Oncology*, 15, 567-578. doi:10.1002/pon.990

Williams, G. C. (2002). Improving patient's health through supporting the autonomy of patients and providers. In E. L. Deci & R. M. Ryan (Eds.), *Handbook of self-determination research* (pp. 233-254). Rochester, NY: University of Rochester Press.

Williams, G., Freedman, Z. R., & Deci, E. L. (1998). Supporting autonomy to motivate patients with diabetes for glucose control. *Diabetes Care*, 21, 1644-1651. doi:10.2337/diacare.21.10.1644

Williams, G. C., Gagne, M., Ryan, R. M., & Deci, E. L. (2002). Facilitating autonomous motivation for smoking cessation. *Health Psychology*, 21, 40-50. doi:10.1037/0278-6133.21.1.40

Williams, G. C., McGregor, H. A., King, D., Nelsom, C. C., & Glasgow, R.E. (2005). Variation in perceived competence, glycemic control, and patient satisfaction: Relationship to autonomy support from physicians. *Patient Education and Counseling*, 57, 39-45. doi:10.1016/j.pec.2004.04.001

Williams, G. C., Grow, V. M., Freedman, Z. R., Ryan, R. M., & Deci, E. L. (1996). Motivational predictors of weight loss and weight-loss maintenance. *Journal of Personality and Social Psychology*, 70, 115-126. doi:10.1037/0022-3514.70.1.115

Williams, G. C., McGregor, H. A., Freedman, Z. R., Zeldman, A., & Deci, E. L. (2004). Testing a self-determination theory process model for promoting glycemic control through diabetes self-management. *Health Psychology*, 23, 58-66. doi:10.1037/0278-6133.23.1.58

Williams, G. C., Rodin, G. C., Ryan, R. M., Grolnick, W. S., & Deci, E. L. (1998). Autonomous regulation and long-term medication adherence in adult outpatients. *Health Psychology*, 17, 269-276. doi:10.1037/0278-6133.17.3.269

World Health Organization (2003). *Adherence to long term therapies: Evidence for action*. World Health Organization.

Wu, Z., Detels, R., Ji, G., Xu, C., Rou, K., Ding, H., & Li, V. (2002). Diffusion of HIV/AIDS knowledge, positive attitudes, and behaviors through training of health professionals in China. *AIDS Education and Prevention*, 14, 379-390. doi:10.1521/aeap.14.6.379.24074

Yun, L. W., Maravi, M., Kobayashi, J. S., Barton, P. L., & Davidson, A. J. (2005). Antidepressant Treatment Improves Adherence to Antiretroviral Therapy Among Depressed HIV-Infected Patients. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 38(4), 432-438.

Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K. (1988). The multidimensional scale of perceived social support. *Journal of personality assessment*, 52, 30-41. doi:10.1207/s15327752jpa5201_2

Zigmond, A. S., & Snaith, R. P. (1983). The hospital and depression scale. *Acta Psychaitr Scand*, 67, 361-370.

APPENDIX A

Interview Protocol: People's experiences with their HIV-treatments and health care related experiences

A. Autonomy as related to HIV-treatment adherence

1. Who or what do you think its responsible for your health? (if the interviewee is uncertain how to answer this question - I will given an example) and say: "For example, do you think you have control over your health? Do you think that by taking your HIV medication you can improve your health? or is your health out of your control?"
2. Do you have an HIV Specialist or a Family Doctor?
3. How important was it for you to have an HIV Specialist/Family Doctor who encourages you to ask questions?
4. How important was it for you to be asked to be involved in the decision to start the medication?

Follow up question

- were you asked?
- Do you think these experiences influence your motivation to take your medication?

Follow up question

- Do you feel that you are thoroughly explained and involved with your HIV-treatment when you visit your doctor's office?
 - Do you think this would influence your motivation to take your HIV medications?
5. Are you experiencing a lot of side effects from your HIV medication?

B. Competence

1. Do you think it is important to adhere to your HIV-treatment?
 - do you think this would influence your motivation to take your HIV medications?
2. How difficult/easy is it for you to take your medications?
3. Do you feel that you can continue taking the medication even when it is interfering with your daily activities? (Self-efficacy)
4. Have you ever had difficulties accessing health information?

- Is there someone/organization that you can go to for help with health related paper work?

5. When your viral load is undetectable, do you stop using your medications?

C. Relatedness

1. What have been some your experiences with health care professionals?

Follow up questions:

- How did that make you feel?
- Have you found yourself avoiding the doctor's office because of these previous experiences?
- Do you think that these experiences influence your motivation to take your HIV medication?

2. Do you think it is important to have a big support of family and friends?

Follow up question:

- Do you feel that you have the support of family and friends?
- how about an intimate partner?
- Do you think their support influences your motivation to take your medication?

APPENDIX B

Demographics Questionnaire

Below are some basic questions about YOU. Please DO NOT attach your name to this or any sheet. Remember that all your answers are confidential and you cannot be identified by any of the pieces of information you provide in this questionnaire package

Today' Date month/year

1. Age (in years) _____

2. How do you describe your gender?:

- ☐ Female
- ☐ Male
- ☐ Female-to-Male transgender)
- ☐ Male-to-Female transgender
- ☐ Two-spirited
- ☐ Inter-sexed
- ☐ Other (please specify) _____
- ☐ Don't know
- ☐ Refused

3. What is your sexual orientation?

- ☐ Straight or heterosexual
- ☐ Gay
- ☐ Lesbian
- ☐ Bisexual
- ☐ Not sure or questioning
- ☐ Other (please specify) _____
- ☐ Don't know
- ☐ Refused

4. In what city do you live now? _____

5. What is your belief system? ***Please check all that apply to you:***

- ☐ Catholic
- ☐ Protestant
- ☐ Christian (if not Catholic or Protestant)
- ☐ Jewish
- ☐ Muslim

- ☐ Hindu
- ☐ Sikh
- ☐ Buddhist
- ☐ Eastern Orthodox
- ☐ African Traditional
- ☐ Aboriginal Traditional
- ☐ New Age
- ☐ Wicca
- ☐ Paganism
- ☐ Agnostic
- ☐ None/Atheist
- ☐ Other (please specify) _____
- ☐ Don't know
- ☐ Refused

The following questions ask about your Ethnicity:

6. In what country were you born? _____

7. How long have you lived in Canada? (in years) _____
 (if you were born in Canada - write "BORN IN CANADA" - do not leave blank)

8. Ethnic Background: What ethnicity do you identify with? ***Please check all that apply:***

- ☐ African (e.g., Nigeria, Ghana, Ethiopia)
- ☐ African-Caribbean (i.e., from the Caribbean and of Black/African descent)
- ☐ Indo-Caribbean (i.e., from the Caribbean and of South Asian descent)
- ☐ Other Caribbean (i.e., from the Caribbean and of other ethnic descent)
- ☐ South Asian (e.g., India, Pakistan, Bangladesh, Sri Lanka)
- ☐ East Asian (e.g., Hong Kong, China, Vietnam, Korea, Philippines)
- ☐ Middle Eastern or North African (e.g., Iran, Israel, Egypt, Morocco)
- ☐ White – British and/or Irish background (e.g., England, Scotland, Wales, Ireland)
- ☐ Italian
- ☐ Portuguese
- ☐ Greek
- ☐ Russian
- ☐ Eastern European (e.g., Ukraine, Romania)
- ☐ White – Other
- ☐ Hispanic / Latino/a
- ☐ Aboriginal
- ☐ Biracial (please tell us) _____
- ☐ Other (please tell us) _____
- ☐ Don't know
- ☐ Refused

9. What are the sources of your personal income? *Please check all that apply to you:*

- ☐ Full time work
- ☐ Part time work
- ☐ Self-employed
- ☐ Disability Pension (ODSP)
- ☐ Old age Pension
- ☐ Worker's Compensation
- ☐ Employment Insurance
- ☐ Ontario works
- ☐ CPP
- ☐ Student loan
- ☐ Volunteering
- ☐ Other (please specify) _____
- ☐ Don't know
- ☐ Refused

10. Are you in a romantic and/or sexual relationship/s (including marriage), either with a single partner or multiple partners?

- ☐ Yes
- ☐ No

IF YES, How long have you been in this relationship? (in months) _____

11. Are you in a romantic and/or sexual relationship/s with multiple partners?

- ☐ Yes
- ☐ No

IF YES, How long have you been in this relationship? (in months) _____

12. Education

- ☐ Elementary school: Grades 1 to 8 - (6 to 14 years old)
- ☐ Less than high school (14 to 18+ years old)
- ☐ Completed high school
- ☐ some college or university (18 years of age and older)
- ☐ College or university
- ☐ Graduate school
- ☐ Doctoral Degree (Medical Degree or Ph.D)
- ☐ Post-doctorate
- ☐ Don't know
- ☐ Refused

13. Your Income (your yearly income): check one

- ☐ \$ 0-19,999
- ☐ \$ 20, 000-29, 999
- ☐ \$ 30, 000-39, 999

- ☐ \$ 40, 000-49, 999
- ☐ \$ 50, 000-59, 999
- ☐ \$ 60, 000-69, 999
- ☐ \$ 70, 000-79, 999
- ☐ \$ 80, 000-100, 000
- ☐ \$ 120, 000 or more
- ☐ Don't know
- ☐ Refused

Here are some basic questions about your medical history. Please do not attach your name. Remember, all of your answers are confidential and you cannot be identified by any information you provide in this package.

14. Was it your choice to begin the HIV-treatment?

- ☐ yes
- ☐ no

15. Was it your choice to begin the HIV-treatment?

- ☐ YES
- ☐ NO
- ☐ Refused to answer
- ☐ Don't know

16. Did you and your doctor decide to begin the HIV-treatment?

- ☐ YES
- ☐ NO
- ☐ Refused to answer
- ☐ Don't know

17. Did you feel the need to begin the HIV-treatment?

- ☐ YES
- ☐ NO
- ☐ Refused to answer
- ☐ Don't know

Open-ended questions:

1. Do you find that you receive enough information regarding your HIV medications from your HIV Specialist or family doctor? Please Explain.

2. Have you ever had difficult time taking your medications as prescribed?

☐ Yes

☐ No

IF YES, what do you think are some reasons for that difficulty?

3. Have you ever felt stigmatized by the actions of a health care professionals (doctors, dentists, nurses, dental technicians, etc)?

APPENDIX C

HIV-related Stigma in Health Care Settings

Stigma: This questionnaire contains items that are related to your visits with any health care professional.

1. It is easier to avoid the hospital than worry about telling them/ or they finding out that I have HIV

1 Strongly Disagree	2 Disagree	3 Neither agree nor disagree	4 Agree	5 Strongly agree	6 Don't know	7 Refused To answer
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2. It is easier to avoid the doctor's office (General practitioner or walking in clinic) than worry about telling them/ or they finding out that I have HIV

1 Strongly Disagree	2 Disagree	3 Neither agree nor disagree	4 Agree	5 Strongly agree	6 Don't know	7 Refused To answer
---------------------------	---------------	------------------------------------	------------	------------------------	-----------------	------------------------------

3. I am hurt by how some health professionals (i.e., doctors, nurses, dental technicians) react to learning that I have HIV/AIDS

1 Strongly disagree	2 Disagree	3 Neither agree nor disagree	4 Agree	5 Strongly agree	6 Don't know	7 Refused to answer
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4. I have avoided going to dental offices because of their reactions to my HIV/AIDS.

1 Strongly disagree	2 Disagree	3 Neither agree nor disagree	4 Agree	5 Strongly agree	6 Don't know	7 Refused to answer
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5. Some of the health care professionals attitudes about HIV/AIDS make me feel worse about myself.

1 Strongly disagree	2 Disagree	3 Neither agree nor disagree	4 Agree	5 Strongly agree	6 Don't know	7 Refused to answer
---------------------------	---------------	---------------------------------------	------------	------------------------	--------------------	---------------------------

6. I have received rolling eyes and glances from health care professionals as a result of my HIV/AIDS health condition						
1 Strongly disagree	2 Disagree	3 Neither agree nor disagree	4 Agree	5 Strongly agree	6 Don't know	7 Refused to answer
7. In hospitals people with HIV/AIDS are treated like outcasts.						
1 Strongly disagree	2 Disagree	3 Neither agree nor disagree	4 Agree	5 Strongly agree	6 Don't know	7 Refused to answer
8. I have never been mistreated by any health care professionals, as a result of my HIV status.						
1 Strongly Disagree	2 Disagree	3 Neither agree nor disagree	4 Agree	5 Strongly agree	6 Don't know	7 Refused to answer
9. I wish HIV clinics had more privacy in the waiting rooms						
1 Strongly disagree	2 Disagree	3 Neither agree nor disagree	4 Agree	5 Strongly agree	6 Don't know	7 Refused to answer
10. I feel like hospitals as not discreet with my HIV/AIDS condition. There is a lack of privacy						
1 Strongly disagree	2 Disagree	3 Neither agree nor disagree	4 Agree	5 Strongly agree	6 Don't know	7 Refused to answer

Flyer Advertising Phase I of this Study

We are seeking participants for a questionnaire study that takes about 60 minutes

1. Must be 18 years or older
2. Must have been on HIV medications for more than six months
3. Can read and write in English

This study has received ethics approval from the University of Windsor.

If you are interested in participating please see a staff member for a questionnaire.

If you have questions regarding the study, please contact:

Name: Elena Ivanova	Name: Elena Ivanova	Name: Elena Ivanova	Name: Elena Ivanova
Phone:	Phone:	Phone:	Phone:
E-mail: ivanova@uwindsor.ca	E-mail: ivanova@uwindsor.ca	E-mail: ivanova@uwindsor.ca	E-mail: ivanova@uwindsor.ca
Name: Elena Ivanova	Name: Elena Ivanova	Name: Elena Ivanova	Name: Elena Ivanova
Phone:	Phone:	Phone:	Phone:
E-mail: ivanova@uwindsor.ca	E-mail: ivanova@uwindsor.ca	E-mail: ivanova@uwindsor.ca	E-mail: ivanova@uwindsor.ca
Name: Elena Ivanova	Name: Elena Ivanova	Name: Elena Ivanova	Name: Elena Ivanova
Phone:	Phone:	Phone:	Phone:
E-mail: ivanova@uwindsor.ca	E-mail: ivanova@uwindsor.ca	E-mail: ivanova@uwindsor.ca	E-mail: ivanova@uwindsor.ca
Name: Elena Ivanova	Name: Elena Ivanova	Name: Elena Ivanova	Name: Elena Ivanova
Phone:	Phone:	Phone:	Phone:
E-mail: ivanova@uwindsor.ca	E-mail: ivanova@uwindsor.ca	E-mail: ivanova@uwindsor.ca	E-mail: ivanova@uwindsor.ca

APPENDIX E

**CONSENT TO PARTICIPATE IN A SELF-ADMINISTERED SURVEY STUDY**

Title of Study: Patient Perceptions of Factors that Influence HIV Treatment.

You are asked to participate in a research study conducted by Elena Ivanova, B.A. (M.A. candidate) under the supervision of Dr. Kathryn Lafreniere (faculty supervisor), from the Department of Psychology at the University of Windsor. The results of this study will be used to contribute to the requirements of the M.A. thesis of the first investigator. The study is in part supported by research funding from the Canadian Institutes of Health Research.

If you have any questions or concerns about the research, please feel to contact:

Elena Ivanova
ivanova@uwindsor.ca

or

Dr. Kathryn Lafreniere
Daytime phone: 519-253-3000
ex.2233
lafren1@uwindsor.ca

PURPOSE OF THE STUDY

The purpose of this study is to explore your experiences with your HIV treatment adherence. Specifically, the study will examine your experiences with taking HIV medication. The results of this study are expected to contribute to a better understanding of how to make HIV-treatments easier for the people who need them.

PROCEDURES

You will be asked to the following things:

There is only one component to this study, which asks you to fill out a questionnaire packet. The survey is expected to take approximately 60 minutes. We will not contact you for follow-up sessions or subsequent studies.

POTENTIAL RISKS AND DISCOMFORTS

Given the potentially sensitive nature of the topic under investigation, it is possible that you will experience some discomfort during filling out the surveys. You may choose to withdraw from the study or take a break at any point. You will be provided with contact information and resources to HIV/AIDS health care specialist/providers.

POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

Participants will gain useful knowledge about themselves through filling out the questionnaires as some of the questions will make them reflect on some of the factors influencing their health, as well as on some of the factors influencing their HIV-treatment adherence. Directly asking participants such questions may lead them to become more aware of their own attitudes towards their health and towards medication adherence.

PAYMENT FOR PARTICIPATION

Upon completion, or termination, of the questionnaire you will be given \$20 (in cash) for your participation.

CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. Your name will not be associated with the questionnaire, or your demographic information. Please DO NOT put your name anywhere. The questionnaires will be stored by the primary investigator; the files will be retained for 6 years following publication of the study. After 6 years, the physical files will be shredded. Information will not be provided to a third party for any reason.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you do not want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so. You also have the option to destroy the questionnaires at any time prior to completion of the research project.

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE SUBJECTS

Research findings will be available in a pamphlet form and posted at the participating AIDS Service Organizations (ASOs). Please inquire onsite staff members at the ASO to direct you to the pamphlet, which will be available after October 2011. Also, in fall 2011 a summary of the results will be posted at <http://www.uwindsor.ca/reb/study-results>, and participants can find the study by searching for the study title " Psychosocial Influences on HIV Treatment Adherence: Utility of the Theory of Self-Determination".

Date when results are available: _October 2011_____

SUBSEQUENT USE OF DATA

This data may be used in subsequent studies.

RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. If you have questions regarding your rights as a research subject, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario N9B 3P4; Telephone: 519-253-3000, ext. 3948; e-mail: ethics@uwindsor.ca

SIGNATURE OF RESEARCH SUBJECT/LEGAL REPRESENTATIVE

I understand the information provided for the study *Patient Perceptions of Factors that Influence HIV Treatment* as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

Initials of Participant

Signature of Participant

Date

SIGNATURE OF INVESTIGATOR

These are the terms under which I will conduct research.

Elena Ivanova

Date

APPENDIX F

Information Sheet: Community Resources

Post-study Resources

If you have any complaints about the study please contact:

Dr. Kathryn Lafreniere
(519) 253-3000 ext. 2233
lafren1@uwindsor.ca

If your concerns were not addressed then please contact the University of Windsor ethics director:

Dr. Pierre Boulos
(519) 253-3000 Ext: 3767
boulos@uwindsor.ca

Health Care Information

The Maple Leaf Medical Clinic: Community and HIV Care

Need a Doctor? Then visit the Maple Leaf Medical Clinic:
<http://mapleleafmedical.com/index.php>

"Having both an Internist with HIV and Hepatitis specialization and an Infectious Diseases specialist "in-house" enhances patients' ability to receive thorough and opinion-leading consultations in a seamless fashion"

70 Carlton St., Toronto, ON, M5B 1L6
Telephone: 416-465-0856 ext 2
Fax: 416-465-8344

Social Place

Long Yang Club – Social Club for gay people of Asian and non-Asian ancestry

Telephone: Dial 416-925-9872 (416-925-XTRA)
e-mail address - toronto@longyangclub.org
website: <http://www.longyangclub.org/toronto/about.php>

Throughout the years their events have included: barbecues, bike rides, bowling, Dim Sum, disco nights, discussion groups, hiking, karaoke, picnics, pool, potluck dinners, skating. "We are trying to create an environment for singles and couples who are looking for an alternative social outlet to the bar scene."

Legal Protection and Advice

To contact federal (Canadian government) agencies responsible for protecting human rights or privacy

Canadian Human Rights Commission: www.chrc-ccdp.ca
1-800-999-6899 • TTY 1-888-643-3304

HIV & AIDS Legal Clinic (Ontario): www.halco.org
416-340-7790 or 1-888-705-8889 TTY 416-922-2352 or 1-866-513-9883

HIV-related information

Canadian AIDS Treatment Information Exchange (CATIE)

Knowing helps... 1-800-263-1638 or visit them at <http://www.catie.ca/eng/home.shtml>

Part of CATIE's mission statement is to:

Support and connect people with HIV, other individuals, and organizations to develop, synthesize, share and apply HIV knowledge.

Additional Contacts:

AIDS Sexual Health Info. Line-1-800-267-7432

Africans in Partnership against AIDS-416-924-5256

African and Caribbean Council on HIV/AIDS in Ontario-416-977-9955

Bereaved Families of Ontario-1-800-236-6364

Canadian Aboriginal AIDS Network-1888-285-2226

Canadian AIDS Society-1-800-668-2437

Central Toronto Community Health Centres-416-703-8482

Ontario Disability Support Plan: (Toronto) - 416-314-5700

Ontario Drug Benefits- 1-866-811-9893

Voices of Positive Women- 1800-263-0961

Women's Health in Women's Hands- 416-593-7655

Alliance for South Asian AIDS Prevention- 416-599-2727

Anishnawbe Health Toronto- 416-360-0486

Asian Community AIDS Services - 416- 963-4300

Barrett House- 416-869-3619

Maggie's-The Toronto Prostitutes' Community Service Project- 416-964-0150

Miriam Child & Family Support Services- 905-681-7157

Ontario HIV Treatment Network (OHTN) - 416-642-6486

Peel HIV/AIDS Network- 905-362-2025

Queen West Community Health Centre- 416-703-8482

Regent Park Community Health Centre- 416-364-2261

Rexdale Community Health Centre-416-744-0066

Warden Woods Community Centre- 416-694-1138

South Riverdale Community Health Centre- 416-461-1925

Toronto Prostitutes' Community Service- 416-964-0150

Flyer Advertising Phase II of this Study

We are seeking participants for an interview study that takes 35 to 40 minutes

1. Must be 18 years or older
2. Must have been on HIV medications for more than six months
3. Can speak and understand English

Participants will receive \$40 in cash for their participation.

This study has received ethics approval from the University of Windsor.

If you are interested in participating or have questions, please contact:

Name: **Elena Ivanova**
Phone:
E-mail: **ivanova@uwindSOR.ca**

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E-mail: **ivanova@uwindSOR.ca**

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APPENDIX H

**CONSENT TO PARTICIPATE IN A FACE TO FACE INTERVIEW**

Title of Study: Patient Perceptions of Factors that Influence HIV Treatment.

You are asked to participate in a research study conducted by Elena Ivanova, B.A. (M.A. candidate) under the supervision of Dr. Kathryn Lafreniere (faculty supervisor), from the Department of Psychology at the University of Windsor. The results of this study will be used to contribute to the requirements of the M.A. thesis of the first investigator. The study is in part supported by research funding from the Canadian Institutes of Health Research.

If you have any questions or concerns about the research, please feel to contact:

Elena Ivanova
ivanova@uwindsor.ca

or

Dr. Kathryn Lafreniere
Daytime phone: 519-253-3000
ex.2233
lafren1@uwindsor.ca

PURPOSE OF THE STUDY

The purpose of this study is to explore your experiences with your HIV treatment adherence. Specifically, the study will examine your experiences with taking HIV medication. The results of this study are expected to contribute to a better understanding of how to make HIV-treatments easier for the people who need them.

PROCEDURES

You will be asked to the following things:

There is only one component to this study, which asks you to participate in a face-to-face interview. The interview is expected to take approximately 35 to 40 minutes. We will not contact you for follow-up sessions or any subsequent studies.

POTENTIAL RISKS AND DISCOMFORTS

Given the potentially sensitive nature of the topic under investigation, it is possible that you will experience some discomfort during the interview. You may choose to withdraw from the study, and you may choose not to answer particular questions and can take a

break at any point. You will be provided with contact information and resources to HIV/AIDS health care specialists/providers.

POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

Participants will gain useful knowledge about themselves through filling out the questionnaires as some of the questions will make them reflect on some of the factors influencing their health, as well as on some of the factors influencing their HIV-treatment adherence. Directly asking participants such questions may lead them to become more aware of their own attitudes towards their health and towards medication adherence. Also, this being a face-to-face interview, participants will have an avenue for having their voice heard and the opportunity to raise relevant concerns related to their health care experiences.

There are potential benefits to the scientific and medical community as well as society.

PAYMENT FOR PARTICIPATION

Upon completion, or termination, of the questionnaire you will be given \$40 (in cash) for your participation.

CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. Your name will not be associated with the interview. Please **DO NOT** use your real name during the interview. The audio tape will be destroyed as soon as the data is recorded on paper. Information that identifies you will not be provided to a third party for any reason.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you do not want to answer and still remain in the interview. The investigator may withdraw you from this research if circumstances arise which warrant doing so. You also have the option to delete the audio recording at any time prior to completion of the interview.

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE SUBJECTS

Research findings will be available in a pamphlet form and posted at the AIDS Committee of Windsor. Please inquire onsite staff members at the ASO to direct you to the pamphlet, which will be available after October 2011. Also, in fall 2011 summary of the results will be posted at <http://www.uwindsor.ca/reb/study-results>, and participants can find the study by searching for the

study title " Psychosocial Influences on HIV Treatment Adherence: Utility of the Theory of Self-Determination".

Date when results are available: _October 2011_____

SUBSEQUENT USE OF DATA

This data may be used in subsequent studies.

RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. If you have questions regarding your rights as a research subject, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario N9B 3P4; Telephone: 519-253-3000, ext. 3948; e-mail: ethics@uwindsor.ca

SIGNATURE OF RESEARCH SUBJECT/LEGAL REPRESENTATIVE

I understand the information provided for the study *Patient Perceptions of Factors that Influence HIV Treatment* as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

Initials of Participant

Signature of Participant

Date

SIGNATURE OF INVESTIGATOR

These are the terms under which I will conduct research.

Elena Ivanova

Date

APPENDIX I

**CONSENT FOR AUDIO TAPING**

Interviewee Name/Initials:

Title of the Project: Patient Perceptions of Factors that Influence HIV Treatment.

I consent to the audio-taping of the interview.

I understand these are voluntary procedures and that I am free to withdraw at any time by requesting that the taping be stopped. I also understand that my name will not be revealed to anyone and that taping will be kept confidential. Tapes are filed by number only and store in a locked cabinet.

I understand that confidentiality will be respected and that the audio tape will be for professional use only.

(Research Participant)

(Date)

Or

(Researchers)

(Date)

VITA AUCTORIS

Elena Ivanova was born in 1984 in Sofia, Bulgaria. Elena along with her parents and her older brother moved to Canada in 1996. She graduated from Pope John Paul II Secondary School in 2002. Following this, she pursued a Psychology Bachelor Degree from York University, and graduated with distinction from the Honours program in 2008. At present, Elena is a candidate for the Master's degree in Applied Social Psychology at the University of Windsor.